

Dignity Therapy: A Scottish Feasibility Study

Audrey Matthews

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DECLARATION OF OWN WORK

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DEDICATION

I looked at the tape recorder, feeling guilty, as if I were stealing what was left of his precious speaking time. "Should we skip it?" I asked. "Will it make you too tired?" Morrie shut his eyes and shook his head. He seemed to be waiting for some silent pain to pass. "No," he finally said. "You and I have to go on. This is our last thesis together, you know." Our last thesis. "We want to get it right" (pp.132-133).

- *Tuesdays with Morrie* (Albom, 1997).



This project is dedicated to the memory of my Morrie, Edward Twomey (8th July 1951 – 17th October 2005), who changed the lives of so many before motor neurone disease changed his.

In order to protect the anonymity of the participants in this study, the research site will be referred to as 'the hospice' throughout this report.

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ABSTRACT

Introduction: Dignity therapy, which has recently been developed to reduce psychosocial and spiritual distress in terminally ill patients, has stimulated substantial interest worldwide. This new form of structured life review has not previously been researched in the United Kingdom. This study aimed to explore the experiences of specialist palliative care patients in Scotland undertaking dignity therapy and to establish whether or not they would recommend it to fellow patients.

Method: Eight patients (seven female and one male) participated in the Dignity Psychotherapy Question Protocol (DPQP), followed by a semi-structured research interview. The interviews were recorded and transcribed verbatim, before being analysed using a grounded theory approach to develop a provisional framework.

Results: The findings suggest that patients perceived dignity therapy in a predominantly positive light. They considered the patient-researcher rapport, in terms of listening and compassion, to be especially helpful and to have facilitated the therapeutic encounter. The analysis also identified four beneficial components of this therapy: a) looking back b) sharing their memories c) getting things off their chest and d) putting their story on paper. Based on their experiences, the majority of patients reported that they would recommend this intervention to fellow patients.

Discussion: Whilst several of the benefits of dignity therapy reported by patients correspond to findings of previous dignity therapy studies, many also fit with benefits reported in the literature from other life review processes. Consequently, it is unclear if dignity therapy is unique as claimed. It is also unclear which features of the rapport were attributable to therapist-specific factors and which may be credited to the intervention itself. However, identified limitations of this study are discussed.

Conclusion: These results suggest that dignity therapy is feasible for patients with advanced illness in Scotland and may even benefit those without observable psychological distress. Nevertheless, given the small sample studied, further research is needed to corroborate these findings.

1.INTRODUCTION

This chapter provides a brief introduction to palliative care and the evidence-base for interventions. Challenges facing end-of-life research are addressed, as is the specific need for more research regarding psychological and spiritual issues of patients with advanced disease. The background to and aims of this study are also outlined.

1.1 Palliative Care

A Brief History of Palliative Care

Hospice care dates back to 1842 in Lyons, France (Saunders, 2006). However, the modern hospice movement began in 1967, when the first research and teaching hospice (St. Christopher's Hospice) was opened by Dame Cicely Saunders and her team in Sydenham, England (Parkes, 2000). Research was immediately prioritised and early studies appraising pain control (Twycross, 1977) and hospice care (Parkes, 1985) greatly influenced the widespread progression of palliative care as a speciality (Hanks *et al.*, 2006b). Since these early days, the field has expanded throughout the developed world and to a lesser extent, the developing world (Doyle *et al.*, 2006). More than 8000 palliative care services, including inpatient and day patient units, as well as hospital- and community-based facilities (Stjernswärd & Clark, 2006), are now spread across almost one hundred countries worldwide (Higginson, 2006).

Doyle *et al.* (2006) distinguished between generalist and specialist palliative care. Generalist care is normally provided primarily by the patient's general practitioner. Specialist palliative care is provided by a multidisciplinary team with specialist training, when the patient's disease is far-advanced and their needs exceed the capability of generalist services. In Scotland, specialist palliative care is predominantly provided by voluntary hospices in partnership with NHS Boards and Trusts (Clinical Standards Board for Scotland, June 2002).

The Objectives of Palliative Care

Palliative care developed as a result of recognised deficiencies in the care of patients with advanced disease (Higginson, 2006). From the beginning, hospice care incorporated two key components: (1) rapid and effectual control of physical symptoms of terminally ill patients and (2) support for patients and their families with psychological, social and spiritual issues (Parkes, 2000). Accordingly, the model of care extended beyond the traditional biomedical model of disease. Current palliative care services retain these holistic aims (Doyle *et al.*, 2006), as is evident in the World Health Organization's definition of palliative care:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2002, p.84)

With the international expansion of palliative care in recent years, there have been considerable advances in the assessment and management of physical symptoms, such as constipation and diarrhoea (Sykes, 2006), fatigue (e.g. Abbey, 2000; Groopman, 1998; Sweeney *et al.*, 2006), nausea and vomiting (Mannix, 2006), and pain (e.g. Breitbart *et al.*, 2006; Hanks *et al.*, 2006a; Portenoy *et al.*, 2006). Hence, the palliation objective of physical symptom management is being achieved with increasing success. In contrast, studies of patients' psychosocial and spiritual suffering in the face of death are distinctly deficient, as is an evidence-base regarding appropriate assessment and intervention techniques for these difficulties (e.g. Cassem, 2000; Chochinov, 2006; Neuberger, 2003). Consequently, palliative care goals for such suffering are not being reached. This is unsatisfactory, given that it has been reported that psychosocial or spiritual issues may impose equal or greater distress on patients with advanced illness than that caused by physical symptoms (e.g. Breitbart *et al.*, 1996; Chochinov *et al.*, 2005; Field & Cassel, 1997).

Palliative care has traditionally been associated with cancer patients and cancer remains the predominant diagnosis (approximately 95 per cent of cases) managed by hospice services in the UK (Hospice Information, 2005). However, it is now accepted that patients with non-malignant diseases, such as cardiac failure, neurological diseases and Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) also come under the speciality's remit (Doyle *et al.*, 2006), and anecdotal evidence suggests that referrals of patients with non-malignant disease to British palliative care services are growing (Fallon, 2006). Consistent with this, the Marie

Curie Cancer Care (MCCC) charity confirmed in 2007 that it would extend its remit beyond cancer (MCCC, December 2007).

1.2 Factors Impacting the Palliative Care Evidence-Base

Cathcart (2006) suggested that the dearth of solid palliative care evidence is perhaps unsurprising given the innumerable methodological challenges facing researchers. This patient group tends predominantly to have complex progressive disease, often with co-morbid conditions in elderly patients, limited prognosis (Hanks *et al.*, 2006b) and rapidly fluctuating symptoms (Kristjanson & Coyle, 2006). Recruiting adequate numbers for studies can be extremely difficult, whilst attrition poses further problems (Llewelyn *et al.*, 1999; Proot *et al.*, 2004). Finding suitable outcome measures to evaluate treatments for these patients can also be arduous (Cathcart, 2006).

According to Kendall *et al.* (2007), central obstacles to embarking upon end-of-life research are the modern personal and societal taboos surrounding death and dying, which can arouse strong emotional reactions. Such taboos may impact the decisions of ethics committees, many of whose members may have little knowledge of palliative care and deem research as an unnecessary burden for these patients (Lee & Kristjanson, 2003). For similar reasons, clinical staff may also act as overprotective gatekeepers (Kendall *et al.*, 2007; Kirsh *et al.*, 2004). They may worry about asking terminally ill patients to discuss sensitive topics whilst they are concurrently experiencing considerable physical and emotional distress in relation to their ill-health (Ingham &

Portenoy, 2006). Likewise, family members, who may be concerned that research will unduly upset and fatigue their loved one, whilst also encroaching upon their remaining family time, may resist research efforts (Hanks *et al.*, 2006b). Unease regarding palliative care research has also been expressed by some researchers (e.g. De Raeve, 1994), who believe that terminally ill patients constitute an extremely vulnerable population.

1.3 Problems with Thwarting Palliative Care Research

At first glance, preventing research participation for palliative care patients seems sensible (MacDonald & Weijer, 2006). Unfortunately however, it assumes that all palliative care patients are so vulnerable that they cannot decide independently regarding participation (Kendall *et al.*, 2007; Mount *et al.*, 1995). MacDonald and Weijer (2006), who acknowledged that these patients require added protection, argued that prohibiting their involvement in research is unjust. Hopkinson *et al.* (2005) suggested that such exclusion may even be unethical.

Moreover, much has been written about the satisfaction felt by terminally ill patients when given the opportunity to partake in research. Kendall *et al.* (2007) noted that such participation can offer the chance to be an active citizen again, as opposed to being a passive patient. It allows patients to contribute to healthcare advances to the benefit of fellow and future terminally ill patients (Hopkinson *et al.*, 2005), thus providing participants with a sense of purpose (Lee & Kristjanson, 2003). Research participation

also offers patients the chance to be heard (Dean & McClement, 2002; Kendall *et al.*, 2007), sometimes in cases where they may have no other opportunity to convey their needs (Bradburn & Maher, 2005; Ferrell & Grant, 2001).

Bradburn and Maher (2005) stressed that the inherent challenges in end-of-life research must not justify inaction, especially when moral and procedural rigour in such studies is achievable (Kendall *et al.*, 2007). Furthermore, research has shown that sensitive issues, such as desired place of death, can be addressed with these patients (Townsend *et al.*, 1990). However, one's cultural context may influence patients' willingness to self-disclose (Ingham & Portenoy, 2006). Given that solutions exist to overcome potential research barriers, MacDonald and Weijer (2006) asserted that it is acceptable to include palliative care patients in research, provided certain conditions are met:

- ◆ The research must be pertinent to these patients;
- ◆ It must be potentially beneficial to them;
- ◆ It must provide an opportunity to further the understanding of their experiences; and
- ◆ Safeguards must be in place to protect participants.

Over and above these conditions, Kendall *et al.* (2007) highlighted the importance of providing sufficient psychological support to the research team involved.

Given the growing awareness of major gaps in the palliative care evidence-base, calls have been made to resolve the situation in order to guide palliative care practitioners (e.g. Fallon, 2006; Hanks *et al.*, 2006b; Scottish Partnership for Palliative Care, 2007). One serious concern of leading writers in the field is that patients will suffer if an evidence-base is not developed to support funding applications (e.g. Lee & Kristjanson, 2003; MacDonald & Weijer, 2006). Furthermore, as life expectancy grows and there is an increasingly elderly population, there will be greater public demand for palliative care (WHO, 2004).

1.4 Psychological Issues at the End of Life

One key area which has suffered as a consequence of the relative lack of research is that of the psychological issues experienced at the end of life. It is known that feelings of anger, anguish, denial, guilt, hopelessness, isolation, loss, melancholy, panic and worry occur intermittently for the majority of terminally ill patients (Block, 2006; Woodruff & Glare, 2006), with psychiatric disturbance frequently increasing as patients become sicker (Block, 2006). However, some patients display extraordinary bravery and hope (Viederman, 2000).

Research suggests that anxiety and depression are the most widespread psychiatric disorders seen in palliative care settings (Block, 2006). Prevalence rates for depression in cancer patients range widely from 1-40 per cent (Wilson *et al.*, 2000), depending on the disease type, stage and context studied (Stiefel *et al.*, 2001; Wilson *et al.*, 2000).

Lack of agreement as regards assessment measures and diagnostic criteria has made it difficult to determine accurate prevalence rates (Block, 2006), as has the fact that many clinicians believe mistakenly that depression is an appropriate response in the face of advancing illness and therefore, refer few patients for treatment (Wilson *et al.*, 2000). Acknowledging the divergent figures available, Vachon (2006) proposed that rates of clinical depression in advanced cancer patients are similar to those in patients with other major illnesses, which Stiefel *et al.* (2001) estimated to be 25 per cent. It has also been suggested that the prevalence of depression in cancer patients has decreased in the past two decades, possibly due to improved outcomes associated with medical advances, as well as reduced stigma surrounding cancer diagnoses (Block, 2006).

The literature suggests that clinical anxiety, which frequently presents with depression (Payne & Massie, 2000), also affects approximately 25 per cent of cancer patients (Block, 2006). Other commonly associated psychiatric presentations include adjustment disorder, delirium, obsessive-compulsive disorder, phobias, panic disorder and post-traumatic stress disorder (Block, 2006). Anxiety symptoms can also be induced by medications, including corticosteroids and neuroleptic drugs (Payne & Massie, 2000). The impact of end of life issues on patients with chronic psychiatric disturbance, such as schizophrenia and bipolar disorder, is not well understood (Goldenberg *et al.*, 2000).

Block (2006) suggested that the psychological impact of one's disease varies considerably amongst patients and depends upon factors, such as their age, the meaning the illness holds for them, its impact on their sense of self, their coping style, their levels

of social support and the presence of concurrent stressors, such as financial strain. Unresolved past difficulties, sorrow concerning present and expected losses, uncertainty regarding the future and worries about loved ones may also play a part, as might intense physical symptoms (e.g. pain), pre-existing or newly occurring psychiatric disorders, complex family relationships or dissatisfaction with carers. Upon receiving a poor prognosis, patients are faced with dramatically changed circumstances and they must re-evaluate their previous roles (e.g. as spouse, parent, friend, employee or boss) (Viederman, 2000). Unsurprisingly, Coyle (2006) reported that living with death looming can be 'hard work'.

1.5 Spiritual Issues at the End of Life

Spiritual issues, which have received increasing attention in the palliative care literature over the past two decades, remain poorly understood (Murray *et al.*, 2004; Sinclair *et al.*, 2006). Chochinov (2006), who indicated that psychiatric classifications do not account for the full range of distress responses in the face of advancing illness, cited spiritual anguish as an example of distress which can be missed or misclassified. Acknowledging common difficulties defining and recognising spiritual distress (e.g. Sinclair *et al.*, 2006; Unruh *et al.*, 2002), Kearney and Mount (2000) explained that 'at the root of such distress is a rupture, a disconnection and a resulting alienation within individuals from that aspect of their deepest selves that gives meaning, hope and purpose' (p.363). Similarly, Rousseau (2003) described these concerns, which are fundamental to human nature, as relating to purpose and meaning in life. Interchangeably called 'spiritual' or

‘existential’ issues, Doyle *et al.* (2006) reported that these concerns seem to be a world-wide phenomenon distinct from one’s religious affiliation. However, this division of religious and spiritual concerns is contentious (Sinclair *et al.*, 2006).

Woodruff and Glare (2006) stated that any significant life event can lead one to question the meaning and purpose of life. However, life-threatening events are most likely to do so. Moreover, different serious illnesses (e.g. heart failure and lung cancer) can bring about different spiritual needs (Murray *et al.*, 2004). As patients experience a loss of function as their illness progresses, they suffer a blow to the meanings and values they have held during their lives (Spira, 2000). As death approaches, dying patients often search for some existential meaning (Kearney & Mount, 2000). Questions such as, ‘What has been the meaning and purpose of my life?’ (Noble & Jones, 2005), ‘Why do people live?’, ‘Why do people die?’ (Rousseau, 2003) and ‘Why me?’ (Murray *et al.*, 2004) commonly intensify as death draws near (Highfield, 1992). Patients question their achievements, desire resolution for outstanding issues and speculate about how others will remember them, usually hoping that this will be in relation to non-material things, such as the good that they have done (Fürst & Doyle, 2006).

Although Noble and Jones (2005) reported that patients or their families may perceive such self-questioning as an unhelpful deliberation upon their lives, Holland *et al.* (1999) reported that searching for meaning can be particularly helpful for terminally ill patients. Being able to discover and preserve a sense that life is purposeful and meaningful facilitates hope (Herth, 1990) and endurance of physical symptoms, and defends against

depression and a yearning for an accelerated death (Block, 2006). Given this, Fürst and Doyle (2006) cautioned against assuming that concern with spiritual issues in the terminal phase constitutes 'suffering'. They suggested that although some patients are unhappy with aspects of their past, others find looking back a positive, reflective process. They added that such ponderings about one's life are natural and common, with approximately 75 per cent of palliative care patients asking questions, which suggest contemplation of spiritual issues.

However, finding meaning in the face of incurable illness is an immense undertaking (Breitbart *et al.*, 2004) and for some patients, especially those who are unable to do so, spiritual questioning does cause distress (Block, 2006; Coyle, 2006). Kissane *et al.* (2001) have classified a specific constellation of spiritual distress symptoms (e.g. hopelessness, loss of meaning and helplessness, which can result in a wish to die) as 'demoralisation syndrome'. Unlike those with depression who cannot enjoy the present, the despair of patients with demoralization syndrome is thought to be future-oriented (Woodruff & Glare, 2006). However, questions have been raised regarding the research evidence to support this classification (Block, 2006).

Although more instruments are needed to assess spiritual distress in palliative care patients (Kissane & Street, 2006), Rousseau (2003) suggested that the best way to detect it is to build rapport with these patients, before enquiring directly about death-related worries or thoughts. However, it has been suggested that caregivers do not routinely do this (e.g. Chochinov, 2006; Kearney & Mount, 2000; Murray *et al.*, 2004). This may be

due to time pressures, limited understanding of spiritual issues, the paucity of treatment options available and the fact that patients conceal their spiritual distress (Murray *et al.*, 2004). According to Block (2006), successful coping in palliative care patients is aided by thorough consideration of physical, psychological and spiritual concerns, which often present together (Chochinov *et al.*, in press). Given that untreated distress may interfere with disease management, it is essential that suffering is addressed (Payne & Massie, 2000; Woodruff & Glare, 2006). Moreover, when distress is treated effectively, terminally ill patients may improve their quality of life and regain a sense of meaning in the final months, weeks and even days of their lives (Wilson *et al.*, 2000).

1.6 Psychotherapeutic Interventions for the Terminally Ill

Although the importance of detecting and addressing psychological and spiritual distress at the end of life is now evident, few studies have evaluated interventions to treat these forms of suffering (Block, 2006). Accordingly, the limited evidence-base makes symptom management an onerous task for palliative care clinicians and the distress of many patients remains untreated (Passik *et al.*, 2004). The usefulness of psychotherapy with palliative care patients has not been extensively researched (Wilson *et al.*, 2000). Its possible worth for many of these patients may be undervalued, which is unfortunate given that psychotherapy can allow patients to address difficult feelings and unresolved issues (Rodin & Gillies, 2000). Vachon (2006) suggested that even patients who do not have a formal psychiatric illness may benefit from such support.

In a review of the current evidence-base for psychotherapeutic interventions at the end of life, Block (2006) reported that some potentially useful interventions have been proposed. These include cognitive-behavioural therapy (CBT) (e.g. Turk & Feldman, 2000), existential therapy (e.g. Spira, 2000), insight-oriented psychotherapy (e.g. Rodin & Gillies, 2000), interpersonal therapy (e.g. Markowitz *et al.*, 1992), psychodynamic life narrative (e.g. Viederman, 2000) and supportive psychotherapy (e.g. Rodin & Gillies, 2000). Breitbart (2002) also highlighted the merits of group psychotherapy (e.g. CBT and psychoeducation) for patients with advanced disease. However, Chochinov (2006) argued that some of these therapies (e.g. insight-oriented therapy and interpersonal therapy) may not be suitable for terminally ill patients, because of the extended period often necessitated for their application. Similarly, Cathcart (2006) emphasised that the value of CBT in the final stages of life remains uncertain, given problems with increasing fatigue and frailty, alongside decreasing concentration. Rodin and Gillies (2000) agreed that therapy needs to be modified in many practical ways (e.g. timing, depth of therapy) when working with terminally ill patients.

Life Review

One psychotherapeutic intervention, which was first developed in elderly care but has received extensive attention in the palliative care literature recently, is that of life review (e.g. Coyle, 2006; Rousseau, 2003; Trueman & Parker, 2004). This intervention has been influenced considerably by Erikson's (1950, 1982) work on psychosocial development and Butler's (1963) paper, which promoted the benefits of life review. Existing in many formats, this procedure can incorporate telling one's life story, drawing

up one's family tree, genogram or lifeline, looking through photographs and belongings, and sharing personally significant music with a caregiver, who may or may not be a therapist. Life review is usually undertaken during structured appointments, which last approximately an hour and are spread over many weeks or months.

Haight *et al.* (2003) and Trueman and Parker (2004) concurred that although the terms 'reminiscence' and 'life review' have been used interchangeably in the literature, they are different processes. Reminiscence tends to be informal, less structured, less purposeful and less therapeutic than life review, which is usually well-prepared, focused, formal and restorative. Trueman and Parker (2004) described life review as a process of sorting out and evaluating both the positive and negative experiences in one's life, the potential therapeutic benefits of which include reaffirmation of one's self-worth and individuality, diminished sense of loss or loneliness, enhanced understanding of previous and current relationships, renewed importance on positive parts of one's past and a feeling of achievement with regard to one's life. Similarly, Rodin and Gillies (2000) suggested that life review benefits patients' emotional well-being by providing an opportunity to (re)discover meaning in one's history. In addition, Pickrel (1989) observed that even if patients have a longer prognosis, life review can assist them to accept death.

Furthermore, when one's life review is documented, as in Haight *et al.*'s (2003) study, and left as a legacy for others, important lessons and values from a patient's past can be transmitted to younger generations (Jenko *et al.*, 2007). This gives patients a means of

continued existence beyond their death, which can enable their emotional adjustment to their difficult circumstances (Coyle, 2006).

Narrative therapy approaches to life review, which have also been reported to be beneficial for dying patients for similar reasons (e.g. McLeod, 1997; Noble & Jones, 2005), adopt a slightly different approach. They aim to help the dying patient transform a distressing, immobilizing narrative into one which includes optimism. Problems are externalised and the patient's perception of the problem is modified, thus diminishing its impact on them.

The psychodynamic life narrative is an additional form of life review, which has also been reported to benefit palliative care patients' emotional well-being (Viederman, 2000). This intervention, which involves interpretation on the part of the clinician as the patient's story unfolds, helps patients to appreciate their reaction to their illness in the context of their life history and to see it as modifiable (Viederman, 2000).

However, Knight (1986), cited in Garland (1994), observed that 'life review' has become an umbrella term for a diverse range of activities. The ambiguity with which it is often described in the literature can make it difficult to know how to undertake such activities (Edinberg, 1985) or compare their outcomes. Therefore, in an attempt to standardize life review procedures, Haight and Burnside (1992), and Burnside and Haight (1994) provided detailed instructions for undertaking this process with older adults. Similarly, Jenko *et al.* (2007) developed a question protocol, based on Garland

and Garland's (2001) work, to guide such interventions with dying patients. Trueman (2004) reported that giving patients the questions in advance of well-structured life review sessions empowers them and reduces the possibility of the intervention causing undue psychological distress.

In recognition of the benefits of life review approaches within palliative care, Cassem (2000), Chochinov (2007) and Kearney and Mount (2000) have highlighted the therapeutic gains of understanding the patient as a person with a unique personality and life story (i.e. not just a disease). This can impact positively both patients and caregivers alike (Zalenski & Raspa, 2006). Romanoff and Thompson (2006) remarked that all patients with advanced illness need the chance to share their story with a compassionate listener, who shows real interest as the story unfolds. Similarly, Rousseau (2003) pointed out that clinicians, who show compassion, interest and respect, whilst communicating clearly and making time for dying patients, will facilitate open discussions. Kearney and Mount (2000) emphasised that one's interactions reveal one's attitude towards the patient. When caregivers interact in an affirmative manner, patients' dignity (Chochinov, 2007) and worth are validated (Zalenski & Raspa, 2006), and hope is promoted (Herth, 1990). However, when caregivers treat patients as if they no longer matter, they feel as if this is the case (Chochinov, 2007). In addition to these points, Viederman (2000) warned that being pleasant to patients and reassuring them is no alternative for applying one's knowledge to skilfully uncover patients' individual characters and histories.

Despite the importance of these facets of the therapeutic relationship, Rodin and Gillies (2000) observed that physicians, who feel under pressure to respond to dying patients' distress, may underestimate the importance of listening to their story and instead prescribe medication or provide unwanted opinion. Nevertheless, Sinclair *et al.* (2006) reported that there has been limited training for clinicians regarding the development of these key communication skills identified. More recently however, Chochinov (2007) published empirically-based guidelines called, 'The A, B, C and D of dignity-conserving care', aiming to assist clinicians to develop skills in relation to their attitude (A), behaviour (B), compassion (C) and dialogue (D). Higginson (2007) has commended these guidelines as an invaluable contribution to healthcare training.

Although the value of these general therapeutic approaches has been proposed, a lack of therapeutic interventions intended to address the spiritual issues of dying patients specifically remains problematic (e.g. Chochinov, 2006; Fürst & Doyle, 2006; Kissane & Street, 2006). Most interventions for spiritual issues tend to be pharmacological, aiming to simply make patients less aware of their suffering (Chochinov *et al.*, 2005). This contrasts with Spira's (2000) advice that spiritual distress is best addressed truthfully and openly.

In recent years however, efforts have been made to rectify the paucity of spirituality-focussed psychotherapeutic interventions. Breitbart *et al.* (2004) discussed meaning-centred group psychotherapy, based on the work of Frankl (1992). This psychotherapy supports patients in examining pertinent choices and experiences throughout their lives

and assists them to cope with their circumstances with fortitude and dignity. Other psychotherapeutic interventions which appear to show potential include Rousseau's (2000) multi-feature model for addressing spiritual suffering (in Breitbart *et al.*, 2004) and Cole and Pargament's (1999) psychotherapeutic group programme for cancer patients (in Chochinov, 2006). However, given that both these approaches place high importance on religious expression, they are unlikely to be suitable for those with no religious affiliation (Breitbart *et al.*, 2004; Chochinov, 2006).

Dignity Therapy

More recently, a brief, new psychotherapeutic intervention called 'dignity therapy', which is intended for individual use and appropriate at the patient's bed-side, was introduced by Chochinov *et al.* (2005). Based on Chochinov *et al.*'s (2002) dignity model of palliative care, this intervention was designed specifically to address both psychosocial and spiritual issues, with the intention of helping patients to gain a sense of meaning and purpose, thus alleviating distress as death approaches. This therapy, which is a highly structured form of life review, encourages patients to talk about issues that are most important to them and that they would mostly want to be remembered when they die. Consultations are recorded, transcribed and co-edited with the patient, before the latter is given a 'generativity document', which they may choose to present to a loved one.

Chochinov *et al.* (2005) studied the impact of this intervention on both hospice and home-based terminally ill patients, whose diagnoses were predominantly cancer, in

Canada and Western Australia. Dignity therapy showed considerable benefits for most of the study's one hundred participants, based on pre- and post-intervention measures of depression, desire for death, hopelessness, sense of dignity, sense of purpose, sense of meaning, suicidality and will to live. Of note, improvements were reported even by patients who had expressed low, pre-intervention psychosocial or existential distress. Furthermore, qualitative data revealed that 91 per cent of participants were satisfied or highly satisfied with the intervention and 81 per cent spoke of additional benefits for family members. Chochinov *et al.* (2005) also reported encouraging preliminary results from a subsequent smaller trial of dignity therapy with patients diagnosed with amyotrophic lateral sclerosis (MND). Also of note, a recent study of sixty family members of deceased patients who had previously undertaken the intervention showed that family members would recommend dignity therapy to others with advanced illness, believing it to have alleviated both the distress of their loved one and their own distress following their loved one's death (McClement *et al.*, 2007).

Since its introduction, dignity therapy has been the focus of substantial interest worldwide. Ferrell (2005) described it as 'a major contribution to advancing care for the terminally ill' (p. 5427). She praised the intervention for its simplicity and brevity, and expressed her enthusiasm regarding Chochinov *et al.*'s (2005) claim that dignity therapy can be delivered by a range of health professionals with experience in psychosocial oncology (e.g. chaplains, doctors and nurses), provided support from a psychologist or psychiatrist is available if needed. Dignity therapy has already been trialled in Australia, Canada, China, Denmark, Japan and the USA, although the complete results are not yet

published. There are also plans to trial this intervention in England and Portugal (H. Chochinov, personal communication, 22 November 2007).

Alternate modes of delivering the intervention are also generating interest. For example, Passik *et al.* (2004) undertook a feasibility study of dignity therapy via videophone with eight home-based cancer patients in the USA and, owing to patients' high satisfaction with the intervention, concluded that telemedicine is another means by which house-bound or rurally-based patients can benefit from this therapy.

1.7 Background to This Study

Whilst undertaking a clinical training placement at the hospice, the researcher became aware of the increasing importance given to life review in the palliative care literature. She noted that although terminally ill patients at the hospice sometimes undertook a life review and occasionally produced a memory book for family or friends, there had been no formal investigation of the benefits and drawbacks of this process for patients. To the researcher's knowledge, there has also been an absence of published research examining similar processes in other Scottish hospices. Given the apparent benefits of dignity therapy on the psychological and spiritual well-being of patients nearing the end of life in Canada, Australia and the USA, the planning of further trials of dignity therapy in countries predominantly outside Europe and the absence of any studies of this intervention in the United Kingdom (H. Chochinov, personal communication, 18 March

2006), the researcher was keen to ascertain if this structured process could benefit patients receiving specialist palliative care in Scotland.

With considerable previous experience working with patients with chronic illness (e.g. cardiac problems, chronic pain and HIV) adopting a biopsychosocial model of patient care (Engel, 1977, 1980), the researcher has for a long time been concerned with attending to patients' holistic needs. Given its specific objective of tackling both psychosocial and existential distress, Chochinov *et al.*'s (2005) intervention held particular appeal for her. Following her clinical training experience working with dying patients, the researcher felt competent to undertake research in this field with the support of expert supervision. Furthermore, in light of the growing recognition of the contribution clinical psychologists can offer the field of palliative care (Haley *et al.*, 2003), she was keen to apply her skills to contribute from a clinical psychology perspective.

From a personal point of view, the researcher regrets that the compelling life stories of both her grandmother and a close friend were not documented before their deaths, despite ample time in which to have done so. Consequently, important historical facts and special memories have been lost forever. These private experiences are likely to have contributed additionally to the researcher's desire to ensure that patients who wish to share and document their story have the appropriate opportunities to do so.

1.8 Aims of This Study

This study set out with two primary aims and further secondary aims. The principal objectives were:

1. To explore the experiences of specialist palliative care patients in Scotland participating in dignity therapy and to ascertain what, if anything, patients found helpful and unhelpful about the intervention.
2. To establish whether or not participants felt that, on the basis of their experience, they would recommend dignity therapy to fellow palliative care patients.

This study also aimed to promote the psychological and spiritual well-being of terminally ill patients with both malignant and non-malignant diagnoses, whilst allowing them the opportunity to discuss issues frequently avoided within Scottish society. It was hoped that participation in this study would help patients to feel a sense of pride in their achievements, as well as a sense of empowerment and satisfaction given their potential contribution to the care of future patients. Furthermore, it was hoped that family members and friends in receipt of a patient's journal would benefit from this approach.

In addition to the aforementioned aims, this study set out to contribute, albeit in a small way, to the palliative care evidence-base. By adopting a qualitative methodology, which

is detailed in the following chapter, it was hoped that this research might shed light upon previously untapped areas of the impact of dignity therapy.

2.METHOD

This chapter presents the research design and methodology, as well as an overview of relevant ethical issues. The means by which the quality and rigour of the study were monitored are also outlined.

2.1 Research Methodology

Research Design

This study was designed to obtain the views of patients receiving specialist palliative care in a Scottish hospice regarding their experience of Chochinov *et al.*'s (2005) intervention, the Dignity Psychotherapy Question Protocol (DPQP). It was decided to exclude quantitative measures, such as the pre- and post- intervention measures employed by Chochinov *et al.*, and instead, to ask patients to describe their perceptions of the intervention via a qualitative interview. It was felt that a qualitative approach would allow patients the opportunity to describe freely their experiences and provide a richer insight into their perceptions of the process than that offered by quantitative measures, which provide fixed response options. It was also hoped that a qualitative method might shed light upon previously untapped aspects of the intervention's impact.

Kristjanson and Coyle (2006), discussing the challenges of palliative care research, suggested that the personal approach of qualitative methods might assist participation

and reduce drop out rates. They also remarked that palliative care patients appreciate the opportunity to participate in qualitative research and to share their experiences with others.

Grounded Theory

A grounded theory approach was chosen for this study. This method of analysis was originally introduced by Glaser and Strauss (1967) in their pioneering book, *The Discovery of Grounded Theory*, which coincided with the authors' studies in 1965 and 1968 of patients' experiences of dying in hospital in the United States. Their 1967 publication provided flexible guidelines for analysing qualitative data in numerous areas of inquiry. Moreover, this early methodology was distinct from others, given the authors' passionate promotion of the development of new ideas and theories from research 'grounded' in data, instead of inferring hypotheses from theories already available, which was the predominant approach in the positivist, quantitative research climate into which their methodology was introduced (Charmaz, 2006). The aim of grounded theory was, therefore, to assist researchers in developing novel theories relevant to the setting under study in order to elucidate social processes (Willig, 2005). However, Charmaz (2006) pointed out that grounded theory is also helpful for descriptive studies, which do not necessarily develop fresh theories.

Since its introduction, grounded theory has been modified many times and its original authors have gone their separate ways, owing to conflicting ideas regarding the theory (e.g. Glaser, 1992, 1998; Strauss & Corbin, 1990, 1998). This research adopted the

constructivist version of grounded theory described by Charmaz (2006), with reference to Strauss and Corbin (1998). The researcher acknowledges however, Charmaz's (2006) point that this is only one of many ways to apply this theory. The version endorsed by Charmaz (2006), and Strauss and Corbin (1998), recognizes the part played by the researcher in interacting with and interpreting the data. It is accepted that the researcher's knowledge and background influence the way the study is undertaken. Accordingly, the findings reported are the researcher's interpretation of the data.

Grounded theory involves 'the progressive identification and integration of *categories of meaning* from data' (Willig, 2005, p.33). Initial interviews are transcribed and analysed via coding procedures – that is, labels are assigned to sections of the data that appear to explain what these pieces of text signify. This then allows for comparisons between different sections of data. Categories emerging from early interviews are incorporated into subsequent interviews and comparisons continue as new data are gathered. This is known as *constant comparative analysis*. The researcher undertakes *negative case analysis* by looking for cases which differ from the majority of the data. Willig (2005) stated that such analysis strengthens the findings and ensures that the density of the data is represented. More data are sought to fill informational gaps, and to test and refine developing ideas, in a process known as *theoretical sampling*. This can involve re-interviewing previous participants or interviewing new ones, often deliberately chosen, to elaborate emerging categories. By refining categories and establishing connections between them, the researcher seeks to present a descriptive explanation of the topic under study (Charmaz, 2006). This process is facilitated by keeping *theoretical memos*

throughout the research process. These memos incorporate the researcher's ideas and observations whilst working with the data, and serve as a useful means by which to track decisions relating to the emerging theory (Willig, 2005). Data collection and analysis continue concurrently, and sampling stops when *theoretical saturation* has been reached - that is, when no fresh categories or properties of current categories are emerging during the coding of interviews (Willig, 2005).

Research Tools

A. Demographics Sheet

This was designed by the researcher to gather basic demographic information about participants. Whilst some information (e.g. marital status and religious affiliation) was obtained from patients, other information (e.g. diagnosis and length of time since diagnosis) was retrieved from their medical notes, with patients' consent. The Demographics Sheet (See Appendix 1) was designed for study administrative purposes only and was not seen by patients.

B. Dignity Psychotherapy Question Protocol (DPQP, Chochinov *et al.*, 2005).

The intervention undertaken in this study comprised Chochinov *et al.*'s (2005) DPQP interview schedule (See Figure 1 overleaf). The protocol consists of eleven questions, which are followed up with further enquiries, as deemed appropriate by the interviewer, in order to gain a fuller picture of the patient's story. Appendix 2 presents both the Patient's Copy and the Researcher's Copy of the protocol. The latter provided additional

space to record information (e.g. the dates the DPQP began and ended) required by the researcher only.

- (i) Tell me a little about your life history, particularly the parts that you either remember most or think are the most important?
- (ii) When did you feel most alive?
- (iii) Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- (iv) What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)?
- (v) Why were they so important to you, and what do you think you accomplished in those roles?
- (vi) What are your most important accomplishments and what do you feel most proud of?
- (vii) Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
- (viii) What are your hopes and dreams for your loved ones?
- (ix) What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parent(s), others)?
- (x) Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- (xi) In creating this permanent record, are there other things that you would like included?

Figure 1: Dignity Psychotherapy Question Protocol (DPQP, Chochinov *et al.*, 2005).

C. Intervention Satisfaction Survey (ISS)

The ISS was a semi-structured interview schedule compiled by the researcher for the post-intervention research interview. Questions were designed to ascertain patients' opinions of the DPQP process. A brief, open-ended schedule comprising four core

questions was used by the researcher who, being new to qualitative research, wished to avoid asking leading or limiting questions. Advanced preparation of initial questions for this purpose was advocated by Charmaz (2006). However, consistent with a grounded theory approach, subsequent interviews were guided by the developing theory and the researcher asked additional, more direct questions relating to the emerging categories. Copies of the ISS schedules used with Patient 1 and Patient 8, respectively are enclosed in Appendix 3.

2.2 Ethics

Ethical Considerations

Before discussing the research procedure, it is important to consider ethical issues pertaining to palliative care research. As this study focused on a very sensitive topic with patients with advanced illness, careful consideration of ethical issues was undertaken during the design of the study. This was done to ensure that the research was carried out to the highest ethical standards, in accordance with the principles enunciated in the Declaration of Helsinki (World Medical Association, 2004), and in line with the ethical standards of both the British Psychological Society (2005) and the University of Edinburgh (November, 2002).

The main ethical issues considered pertinent to this research were as follows:

- ◆ Gaining informed consent;
- ◆ Ensuring confidentiality;
- ◆ Managing patients' fatigue;
- ◆ Managing potential distress of patients;
- ◆ Consideration of the impact of a patient's journal on the recipient(s);
- ◆ Consideration of the issue of mortality; and
- ◆ Safety issues surrounding home visits.

Gaining Informed Consent

MacDonald and Weijer (2006) highlighted the importance of gauging the ability of palliative care patients to make an informed decision regarding research participation, owing to the augmented prevalence of dementia and delirium at the end of life, as well as often subtle cognitive impairments. In order to facilitate informed consent, information about the study and the nature of the interviews was provided by both the recruiter (who worked as a consultant clinical psychologist at the hospice and was clinical supervisor for this study) and the Study Information Pack (See Appendix 4). All patients received a copy of the DPQP when approached initially, so that they would be aware of the questions, and had time to think about and prepare answers in advance of the interviews, if they so wished. In addition, informed consent was facilitated by allowing patients time to read the information given and to discuss any issues with

family, friends, relevant professionals, the recruiter or the researcher (See section 2.5 - Approach and Recruitment of Identified Patients). Potential participants were also provided with the contact details of a Professor of Primary Palliative Care as a source of independent information about the research study.

All patients who were deemed by senior clinical staff to be unable to give informed consent, owing to cognitive limitations or severe psychiatric disturbance, were excluded from the study. Also, if the recruiter had reservations regarding the ability of any patient she approached to give informed consent, she was duty-bound to prevent the patient's participation (Downie & Randall, 2006; Hanks *et al.*, 2006b). Furthermore, when the researcher subsequently met with consenting patients for the first time, she again ensured that they had made an informed choice and still wished to proceed with the interviews. This was undertaken in recognition of Lawton's (2000) observation that patients' physical deterioration over time, alongside the psychological impact of this, may result in their reconsidering participation. Hence, initial consent given by a patient was never assumed during later contact.

Additionally related to consent, Kristjanson and Coyle (2006) argued that palliative care researchers should ensure that patients are not dependent on their care, hence feeling obligated to participate in the research. Consistent with this, the researcher was not involved in the care of patients who attended the hospice during the study. Furthermore, the Patient Information Sheet informed patients that their decision regarding participation would not impact their future care and that they would be free to withdraw

from the study at any time without providing an explanation. The recruiter reiterated these points when she approached potential participants to ensure that they did not feel obligated to her in any way, given her employment at the hospice.

Hanks *et al.* (2006b) warned researchers to be vigilant that the nurturing ambience of palliative care settings may lead patients to feel a strong need to repay carers, hence they consent to participation. Both the recruiter and researcher agreed to remain vigilant for this throughout recruitment and to discourage patients from participating if they stated explicitly that this was their reason for doing so.

Ensuring Confidentiality

Calman (2006) wrote that confidentiality ties in with respect for patients, which was an important aspiration for the researcher. Patients were informed on the Patient Information Sheet that confidentiality would be maintained except where the researcher was concerned for the safety or wellbeing of the patient or others. Accordingly, whilst the hospice clinical team and patients' general practitioners (GPs) were informed of patients' participation in the study, the content of interviews was strictly confidential. At the beginning of the intervention and the subsequent research interview, the researcher reiterated that only she and her research supervisors would have access to the recorded material.

Outpatients who agreed to partake in this study were asked by the recruiter to provide their telephone number so that the researcher could call to arrange suitable interview

times. Given that patients might not have told their families about their participation, they were asked if it was acceptable for the researcher to leave a message should they be unavailable.

Once collected, all data were stored on a password-protected computer kept in a locked room. Any information from the DPQP interviews which identified a patient, but needed to be entered onto the computer for the purposes of preparing a journal, was removed as soon as the patient received their final document(s). Identifying information from research interviews was omitted from transcriptions. All study documents were latterly stored in a locked cabinet in the Clinical Psychology office at the hospice, to which only the researcher and her clinical supervisor have access. The inclusion of patients' quotations in this write-up has been done in such a way that precludes their identification. The same will apply for future presentations arising from this study.

Managing Patients' Fatigue

As advised by Dean and McClement (2002), the researcher gave due consideration to patients' fatigue. All interviews began with a reminder that the patient should tell the researcher if they became tired, so that the interview could be stopped and rescheduled. This point was also mentioned on the Patient Information Sheet (See Appendix 4). Therefore, interview length was guided by patients' fatigue, as verbalised by the patient or perceived by the researcher. For example, one DPQP interview lasted 12.5 minutes owing to a patient's fatigue, whilst another extended to an hour (the maximum time agreed for interviews). Research interviews were generally shorter given that many

patients' health conditions had deteriorated significantly by this time. Breaks were incorporated into interviews as necessitated. Every effort was made to ensure that each patient had their interviews completed within six weeks of the intervention commencing, to avoid unnecessarily prolonging research participation.

Inclusion criteria for this study (See section 2.5) required that patients had not participated in research with a psychological focus in the past two months and were not currently involved in other psychological research. This complied with the advice of Dean and McClement (2002) to ensure that patients are not overburdened with research.

Managing Potential Distress of Patients

As a Trainee Clinical Psychologist with experience working with patients' emotional distress, including six months experience working in a specialist palliative care setting, the researcher was used to dealing with patients' difficulties sensitively. Nevertheless, she was aware of Kvale's (1996) advice that whilst the researcher wants to encourage interviewees to speak openly, it is essential that the interviewer prevents the research interview from developing into therapy. In keeping with this, Kristjanson and Coyle (2006) highlighted the importance of remaining vigilant to the need for referral, with the patient's permission, of distressed patients to appropriate professionals. However, given that the researcher in this study was first undertaking an intervention that was a brief, time-limited therapy with patients prior to their research interview, she was aware that her role may understandably be confusing for participants. Accordingly, it was decided that she would monitor closely participants' emotionality during all interviews. Should

a patient become unduly distressed, the researcher would stop the interview and try to ascertain the nature of the patient's distress. Should the patient wish to continue with the interview, but display sustained distress, they would be encouraged to speak to the clinical staff at the hospice or their family. The patient would also be asked if they would like to speak with the on-site consultant clinical psychologist (whom patients had already met in her capacity as recruiter) regarding their difficulties. If the patient chose to be seen by the consultant clinical psychologist, they would be referred by the researcher. However, despite being prepared for such an event, no patient presented like this during the research.

Given that this was a feasibility study, it was decided to exclude individuals who did not speak English. This was decided to avoid undue distress caused by the need to have an interpreter present, through whom to relay one's words. It was hoped however, that the intervention could potentially be made available to any interested and appropriate patients in the future, should study participants endorse its application.

Consideration of the Impact of a Patient's Journal on the Recipient(s)

Consideration needed to be given to the potential handing over of journals that might cause distress to recipients. Although it was considered unlikely that patients would use the opportunity to knowingly reveal hurtful information to their loved ones, this possibility could not be discounted (Dean & McClement, 2002). Both the Patient Information Sheet and Consent Form (See Appendix 4) made it explicit that any potentially distressing material could not be included in a patient's journal. It was

explained that information that might distress the reader would be discussed and edited by the researcher and the patient during a joint review of the draft. If the text in question referred to an unresolved issue for the patient, the researcher would ascertain if the patient wished to be referred to the on-site consultant clinical psychologist to explore these issues and discuss possible routes to their resolution. It was arranged that if a revised wording could not be agreed between the patient and the researcher, then the latter could not allow the journal to be given to somebody. However, no such circumstances arose during the study.

Consideration of the Issue of Mortality

Mortality was inevitably an issue with this patient population. It was agreed that data belonging to patients who did not complete the process (that is, who dropped out or died before the research interview), were destroyed. Also, when the results of the study were ready for dissemination, the researcher contacted patients GPs to ensure that those patients who had requested a summary of the study's findings were still alive. She also checked the database of deaths at the hospice. This was done to avoid unnecessary distress to bereaved relatives by sending information to deceased patients in error.

Safety Issues Surrounding Home Visits

It was agreed with the Hospice Ethics Committee that in exceptional circumstances, such as when a patient wished to participate in the research, but did not have access to transport, the research could take place in the patient's home. However, the researcher had to be satisfied that her safety was not in jeopardy. Accordingly, in the case of

patients for whom this was relevant, the recruiter and the researcher consulted with the clinical team to ascertain if they had any concerns for the researcher's safety should she undertake home visits. Prior to visiting a patient's home, the researcher informed the recruiter where and when she was going. She also made contact with the recruiter following the visit, to confirm that it had been completed safely and to update her regarding any arising issues.

Ethical Approval

Ethical approval was obtained from the Hospice Ethics Committee on the 26th July 2006 following minor amendments to the original research proposal. The study was registered with the local NHS Research and Development Office, who expressed their satisfaction with the study design on the 22nd November 2006, pending full ethical approval. This was subsequently granted by the Regional Research Ethics Committee on the 20th December 2006, following further minor amendments. A copy of all relevant approval letters has been included in Appendix 5. Details identifying the hospice have been erased from the documentation. However, these approval letters are available in full for inspection upon request.

2.3 Honorary Contract

Once all ethics procedures were completed, the researcher was granted an honorary contract from the hospice for the purposes of the research. This was necessary given the hospice's charitable status.

2.4 Staff Briefing

Casarett *et al.* (2001) recommended that staff education be prioritised, in recognition of the problems often posed by the reluctance of hospice staff to allow research in their setting. For this reason, before the study commenced, the clinical team at the hospice was invited by the researcher to one of two thirty-minute sessions to hear about the research. Staff were encouraged to take the handouts provided, including a Staff Briefing Handout and Flowchart of the Research Process (See Appendix 6). They were also invited to familiarize themselves with the inclusion and exclusion criteria, which were detailed on the back of the Suitable Inpatients List and Suitable Outpatients List that they would be required to complete when identifying potential participants (See Appendix 7). Staff were additionally introduced to the Inpatient and Outpatient versions of the Message for Researcher sheets (See Appendix 8), which were designed to save staff time when they wished to inform the researcher of a patient's request to speak to her regarding the research. During these sessions, staff queries were welcomed in order to facilitate maximum understanding of the study. The contact details of the researcher were also provided, should staff have any further questions.

Given that hospice staff had previously known the researcher during her clinical training placement there, these briefing sessions also highlighted the researcher's altered role for the purposes of the research. Accordingly, the clinical team was reminded that the usual patient referral process to the Clinical Psychology Service applied during the study.

2.5 Participants

Inclusion and exclusion criteria were based upon those cited in many previous palliative care research publications.

Inclusion Criteria

1. A terminal illness (malignant or non-malignant disease) associated with a life expectancy of <12 months;
2. Patient aware of his/her prognosis;
3. Minimum age of 18 years;
4. English speaking;
5. Willingness to provide verbal and written consent;
6. On the basis of clinical consensus, no cognitive impairments deemed to contraindicate the ability to give informed consent and to participate in the research interviews;
7. Commitment to 4–5 contacts with the researcher;
8. Has not participated in research with a psychological focus in the past two months; &
9. Not currently involved in other research with a psychological focus.

Exclusion Criteria

Patients who were unable to meet the inclusion criteria above, or who were deemed to be unsuitable for any other reason (e.g. severe psychiatric disturbance, including psychosis) by senior clinical staff overseeing their case, were excluded from this study.

Pilot Study

Hanks *et al.* (2006b) highlighted the value of undertaking a pilot study to examine the specifics of the preliminary research design. Accordingly, prior to patient recruitment, pilot interviews were undertaken with two friends (one male and one female), both of whom were mental health professionals in their forties and to their knowledge, physically well. Although the pilot participants differed from the expected study participants, these preliminary interviews proved very insightful. They allowed the researcher the opportunity to practise using the digital recorder (Sony ICD-SX56) and its associated computer software. This demonstrated the value of having recording equipment, as the researcher could listen attentively to interviewees rather than taking copious notes whilst trying to do so. The pilot study additionally provided an opportunity to practise delivering the questions, to ascertain interviewees' perception of them and to practise transcribing the responses. One pilot participant recommended that patients be reminded that they are not obliged to answer anything with which they feel uncomfortable.

The researcher additionally returned to the pilot participants a week later to ascertain any lasting impact of the questions. Both respondents expressed having found the process very positive and thought-provoking, with no lasting negative impact.

Prior to the study commencing, the researcher also arranged to be interviewed herself by a close friend and clinical colleague using the DPQP. This was consistent with Garland and Garland's (2001) advice to undertake one's own life review before embarking on

such work with others. This remarkably stimulating experience allowed the researcher to gain some insight into what it might be like being 'in the participant's shoes'. It highlighted the complexity of some of the questions and the need for considerable time to prepare comprehensive responses. This interview was felt to have further enhanced the researcher's sensitive delivery of the questions in the main study.

Identification of Suitable Patients

Doctors and nurses identified suitable patients based on the study criteria. It was agreed that suitable inpatients who had been temporarily admitted for symptom control could commence the process whilst an inpatient and continue it, if appropriate, as an outpatient. The names of suitable patients were recorded by staff on either a Suitable Inpatients List or a Suitable Outpatients List. Completed lists were signed by a senior member of clinical staff (doctor or sister in charge) to ensure that patients' suitability had been confirmed. For convenience, these lists were then given to the recruiter at the weekly multidisciplinary team meeting, where the suitability of patients was further discussed when time permitted.

Approach and Recruitment of Identified Patients

Next, the recruiter approached identified patients. She visited the bedsides of inpatients and met with outpatients at the Outpatients Service. She arranged to speak to patients at their earliest convenience, at which point she gave them a Study Information Pack (See Appendix 4) which included:

- ◆ Letter 1 - Patient Invitation to Participate in Research;
- ◆ Patient Information Sheet;
- ◆ Consent Form; and
- ◆ Dignity Psychotherapy Question Protocol – Patient's Copy.

The recruiter offered to go through the information with each patient. She emphasized that the patient was welcome to discuss the study with family, friends and those professionals (including the researcher) listed on the Patient Information Sheet, before deciding whether to participate. In the case of inpatients, the recruiter returned 48 hours later. If an inpatient had not yet decided regarding participation, they were given another 24 hours to do so. If following this additional period, the patient was still undecided and did not wish to clarify anything about the research, it was assumed that they did not wish to participate. The recruiter returned one week later to outpatients. If an outpatient had not decided, they were given another week within which to do so. If following the second week, the patient was still undecided and did not wish to clarify anything about the study, it was assumed that they did not wish to participate. All undecided patients were told that they could let the recruiter know via nursing staff should they wish to take part in the study thereafter.

Inpatients had less time to decide regarding participation as their disease was likely to be more advanced than outpatients'. This necessitated administration of the intervention at the earliest opportunity, so that inpatients had an optimal chance of completing their journal and the research interview. Also, many outpatients attended the Outpatients

Service weekly. Allowing them to decide between attendances meant that they would not have to be disturbed at home in the meantime.

If an inpatient wished to speak to the researcher before deciding, the recruiter explained that the researcher would visit them when next at the hospice. The dates when the researcher would be there were posted in designated hospice locations where they were readily visible to all staff. If an outpatient wished to speak to the researcher before deciding, the recruiter asked for their telephone number so that the researcher could call to answer any questions.

If a patient agreed to participate, the recruiter requested their completed Consent Form, which she went through with the patient to ensure informed consent. In the case of one outpatient whose immobility prevented them from signing the Consent Form, verbal consent was provisionally accepted by the recruiter. The recruiter explained to consenting inpatients that the researcher would visit on her next research day in order to arrange appointments to commence the intervention. She explained to consenting outpatients that the researcher would telephone in order to arrange these appointments. The recruiter then indicated to staff that these patients had agreed to participate in the study. She also recorded patients' decisions on either the Suitable Inpatients List or the Suitable Outpatients List, before giving these to the researcher, along with completed Consent Forms, as soon as all listed patients had been approached and decided regarding participation.

Prior to the study, it was decided that if a patient declined initially, but later requested to participate in the research, the researcher would speak to senior clinical staff overseeing the case, who would decide on the appropriateness of the patient's inclusion at that point. If it was felt that the patient no longer met the study criteria, they would be told in person (inpatient) or by telephone (outpatient) by the researcher that clinical staff at the hospice felt that their participation was no longer appropriate, as the study might contribute to too much fatigue. The patient would also be given this information by letter (See Letter 3 – Appendix 9), which would be copied to the patient's GP and the relevant hospice staff. However, no such situation arose during the research.

Initial Contact Between Researcher and Consenting Patients

The researcher visited the bedsides of consenting inpatients to introduce herself and to arrange convenient interview times. She went through patients' Consent Forms with them to ensure that they had made informed choices and still wished to proceed. Appointments were arranged in as close succession as possible, given a patient's health status and the researcher's allocated research time. All patients were given a written record of the appointments (See Letter 4 - Appendix 10). The researcher also recorded interview times in the Ward Diary so that patients could be reminded of these. For patients residing in shared rooms, the researcher booked a consulting room at the hospice to ensure privacy for these appointments. It was arranged that if a patient in a shared room had mobility problems which precluded them from getting out of bed for the interviews, they would be offered to be taken in their bed to another, more private

room. However, this was not necessitated during the research. If a patient felt too unwell to undertake the interview, an alternate time was arranged.

The researcher telephoned all consenting outpatients. She reminded outpatients of that to which they had consented, prior to arranging appointments. Every effort was made to ensure that appointments coincided with patients' allocated outpatient day(s) at the hospice, where a consulting room was booked for the appointments. Interviews were arranged in as close succession as possible and documented on a letter for the patient. As previously mentioned, home visits were also accommodated, when considered both necessary and safe.

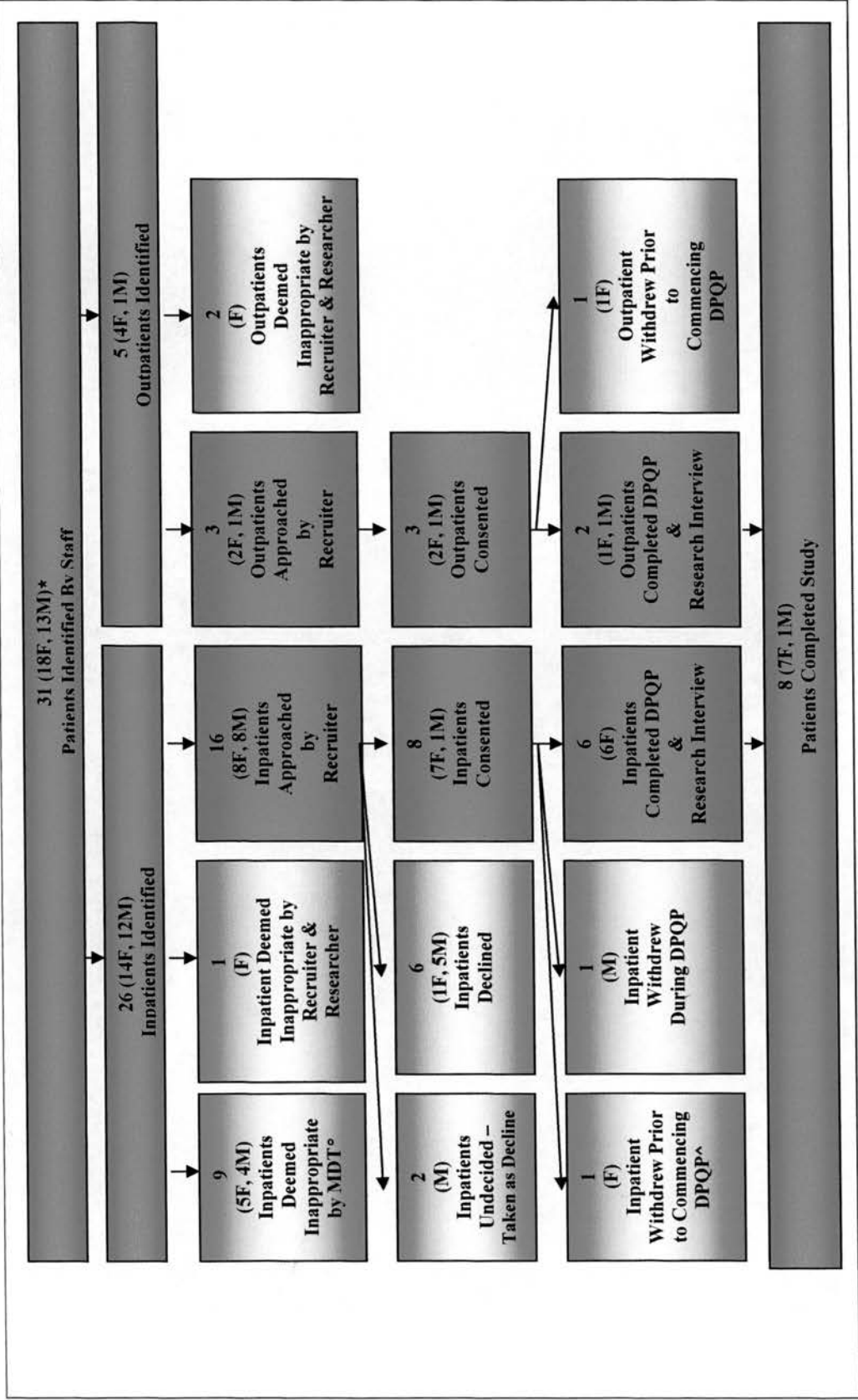
Throughout the recruitment period, the recruiter kept the clinical team up-to-date regarding the progress of participant numbers at the weekly team meeting. In addition, the researcher put up Research Update Posters (See example – Appendix 11) at regular intervals in designated locations in the hospice, where they were readily visible to staff.

Research Participants

In total, 31 patients (26 inpatients and 5 outpatients) were identified by staff as potentially suitable for this study. Nine identified inpatients were subsequently considered inappropriate by the clinical team at the weekly meeting, whilst another inpatient and two outpatients were deemed inappropriate by the recruiter and researcher. Reasons for considering identified patients as unsuitable included:

- ◆ Apparent intermittent confusion;
- ◆ Deterioration in health;
- ◆ Planned hospital transfer;
- ◆ Prognosis likely to exceed 12 months; and
- ◆ Recent completion of a memory book, which might influence the research interview.

Accordingly, nineteen patients (16 inpatients and 3 outpatients) were approached by the recruiter. Eleven patients (8 inpatients and 3 outpatients) consented to participation and six inpatients declined the invitation to participate. A further two inpatients were undecided when approached for a second time by the recruiter and hence, were considered as opting out of the research. Of those patients consenting to participation, one inpatient and one outpatient subsequently withdrew prior to commencing the DPQP, whilst another inpatient withdrew following the first DPQP interview. Accordingly, eight patients (6 inpatients and 2 outpatients) completed this study. Figure 2 shown overleaf presents this information in diagrammatic form and additionally includes a gender breakdown. Of note, four inpatients who began their research participation as inpatients, but later became outpatients and were seen by the researcher at home, are listed as inpatients. Participants' demographic details are summarised in the Results chapter of this report.



* M: Male, F: Female
 ° MDT: Multidisciplinary Team
 ^ DPQP: Dignity Psychotherapy Question Protocol

Figure 2: Patients Identified, Approached and Recruited.

2.6 Informing Relevant Professionals About Patient Participation

A letter (See Letter 2 – Appendix 12) was sent to the GPs of all consenting patients to inform them that these patients had agreed to partake in the study and that their inclusion has been approved by senior clinical staff at the hospice. This letter was copied to relevant hospice staff (e.g. doctors, the sister overseeing the Outpatient Service and community palliative care nurse).

2.7 Intervention

The researcher subsequently undertook the DPQP individually with patients over the course of 1–3 interviews, depending on the number required to complete the protocol. Consistent with the advice of Kvale (1996), at the beginning of their first interview, patients were briefed again regarding the nature of the questions. The researcher also went over outpatients' Consent Forms with them, given that contact had hitherto been by telephone. In the case of one outpatient, alluded to earlier, whose immobility prevented them from signing the form during recruitment, the initial interview began by recording the patient giving consent to each question, which the researcher read aloud. The patient's spouse was also present to verify that consent had been given freely.

Prior to beginning the intervention, patients were reminded that confidentiality would be maintained except where the researcher was concerned for the safety or wellbeing of the patient or others. They were also informed that there was no obligation to answer anything that caused discomfort. Patients were reminded that the interviews would be recorded and they were given the opportunity to ask questions. They were

also asked to tell the researcher if they became tired, so that the interview could be rescheduled.

Prior to commencing the protocol, all patients were asked to whom, if anybody, they wished to leave their journal – that is, the formal written record of their responses to the DPQP, akin to Chochinov *et al.*'s (2005) generativity document. If a patient wished to have no journal, this was agreed. Arrangements were also in place to accommodate patients who wished to have their journal destroyed upon its completion. However, no such request was made.

Once the DPQP commenced, questions were delivered slowly to prevent the patient from feeling rushed and every effort was made to keep the atmosphere relaxed. All interviews were followed by a debriefing, as advised by Kvale (1996). This involved the researcher summarizing the patient's narrative. Once the researcher had concluded the interview and reminded the patient of their next appointment, she recorded in her reflective diary pertinent thoughts and feelings regarding the interview.

Interviews were downloaded onto a password-protected computer and transcribed verbatim by the researcher. All transcriptions were double-checked for accuracy by listening to the recording whilst reading the text. The document was then edited, in line with Chochinov *et al.*'s (2005) procedure, in order to:

- ◆ remove material inappropriate to the final journal (e.g. a visit from staff to indicate the arrival of the patient's transport or a family member dropping in with refreshments for the patient);
- ◆ remove unfinished sentences and link appropriate portions of text;
- ◆ present the patient's life story, in so far as possible, in a sequential order;
- ◆ highlight text which the researcher felt likely to cause distress to the journal recipient(s) and thus, vital to omit or reword with the patient; and
- ◆ find a fitting ending for the journal within the patient's dialogue.

Colloquialisms used by the patient were retained, in order to portray as much of the patient's personality as possible in the journal. Once edited, the researcher prepared the draft journal, using her own design, in black Bell MT font (size 11.5) on white A4 paper. The researcher's speech was presented in bold font to differentiate it from that of the patient, which was presented in regular font. At the end of each document, the following caption was inserted in black, bold and italic font:

***'Interviews recorded on the (date) at (interview location) by
Audrey Matthews, Researcher for her study, 'A Scottish Trial of a Brief
Intervention Based on Dignity Therapy: The Experiences of Palliative Care
Patients.'***

The researcher gave a copy of the draft document to her clinical supervisor, who also checked for any wording which might cause distress to a recipient. The researcher and patient then met for an informal Draft Review Meeting, during which the researcher read the draft journal aloud and the patient decided if there were any changes that they would like made to the document text or presentation, before the

final version was prepared. The researcher discussed with the patient any insensitive wording and where appropriate, more suitable language was considered jointly. When all changes had been decided, the patient chose a title for the final journal and decided how many copies they would like.

In cases where patients were too unwell to listen to the entire draft being read aloud, the researcher endeavoured to present the information as succinctly as possible, highlighting key themes and messages. The patient could not take away the draft document, owing to ethical issues surrounding its preliminary content and the risk of others gaining access to it. However, the patient was assured that when the final journal was prepared, the researcher would still be willing to make changes at the patient's request.

The researcher then compiled the final journal, a fictitious example of which can be seen in Appendix 13, by incorporating all changes agreed at the Draft Review Meeting. The journal title was presented in bold, italic Bell MT font (size 36), with an outside border. The patient was then given the number of copies they had requested, each bound in a clear plastic cover with a solid, black spine. No patient sought further changes at this point. All patients were subsequently left to present their journal(s) to loved ones in their own time.

2.8 Research Procedure

The research interview was scheduled on the same day that the patient received their final journal. The interview began by reminding the patient regarding its rationale,

the nature of the questions and the use of recording equipment. The researcher acknowledged that the patient might feel awkward giving any negative feedback about the intervention, given that she had delivered it. However, she strongly encouraged each patient to speak openly, emphasising the invaluable insight this would provide regarding the perceived impact of the intervention. The patient was reminded to tell the researcher if they became tired, so that the interview could be rearranged. The researcher also reiterated the limits of confidentiality and gave the patient the opportunity to ask questions. The interview then commenced and continued until the patient became tired or had expressed all that they had wished to say. Accordingly, research interviews ranged from 15.20 to 42.28 minutes (mean 26.73; SD 9.16). Following each interview, the researcher wrote points of note in her reflective diary.

2.9 Data Management

As in the case of the DPQP interviews, all research interviews were downloaded onto a password-protected computer. They were transcribed verbatim and any identifying features were removed from the transcripts, all of which were double-checked for accuracy by listening to the recording whilst reading the text.

Qualitative Analysis of Data

Qualitative analysis was undertaken on data from the research interview transcripts, as well as notes from the researcher's reflective diary. Analysis began during the transcription of these research interviews, when the researcher started noticing arising themes. Lacey and Luff (2001) called this process, *familiarisation*.

Transcripts were printed with a wide margin on both sides of the text and formal analysis began with coding. Charmaz (2006) described coding as crucial to making sense of one's data, in order to develop a theoretical understanding of the process under investigation. She advised researchers to delve deep below the surface of the data so as to interpret its implicit meanings. This is described by Strauss and Corbin (1998) as having 'sensitivity' to the significance of one's data. Whilst coding the data, the researcher incorporated Charmaz's (2006) guidelines with those of Strauss and Corbin (1998). The stages undertaken are outlined next.

A. Initial Coding

During the first stage of coding, which was undertaken by hand, the text was analysed line-by-line, as recommended by Strauss and Corbin (1998). This 'gives the researcher analytic scaffolding on which to build' (Charmaz, 2005, p.517). The researcher attended closely to the data, whilst considering the context from which it was gathered. In so far as possible, data were coded as actions, in line with Charmaz's (2006) advice. This was done to avoid unintentionally enforcing concepts from previous theories onto the data and to keep analysis grounded in the data. Initial codes were recorded in the right-hand margin of the page, as draft ideas open to further refinement. The constant comparative method of the grounded theory approach was employed as the researcher reviewed blocks of data side-by-side. Whilst initial coding was under way, the left-hand margin was used to document observations of interest to the researcher, which would later be incorporated into theoretical memos. A brief example of initial coding can be seen in Figure 3 overleaf, whilst a more detailed example is provided in Appendix 14.

MEMO	INTERVIEW TRANSCRIPT	CODING
	Because there's a lot of people too, they've no-one to talk to about it	Having no confidante
This was also mentioned by Patient 2	and then if they're given the chance to say what's really in their heart	Getting things off their chest
	and it gives you like peace inside you...	Inner peace
	I don't know how... to express myself properly	Having difficulty expressing oneself
This was also mentioned by Patients 1 & 2	but I feel that at <i>last</i> , somebody's listening to me.	Feeling listened to

Figure 3: Example of Initial Coding

Computer-Assisted Qualitative Data Analysis Software (CAQDAS)

Following initial coding by hand, further coding was undertaken using NVivo 7 (QSR International Pty. Ltd., 1999-2007), a software package designed to facilitate qualitative analysis. The codes recorded by hand were entered into and frequently refined using this software, as the researcher became more immersed in the data. Comparisons between data continued and possible gaps in the data were noted. Memos were compiled to record the researcher's interpretations and observations during coding. An example of an early memo is shown in Figure 4 overleaf.

Patient 1

P1: It does aye. Aye eh, eh, the likes a, I, I always believe a good listener, a good speaker is one who listens you know as well.

R: In what way do you think that's helped you or that that's been a helpful process?

P1: Well, you get, you're talking to somebody who's listening you know...

R: Ok.

P1: ...not like eh, a lot of people talk to other people and they, they don't take in what the person is saying you know...

P1: Thank you for listening to me.

Patient 2

P2: ...I'm sitting here now. I'm looking at you. I know the type of person you are and em, I know within my heart that I can open up and it's just you and I...

R: Ok. Ok.

P2: ...and that's a *big* help...

R: Right. So...

P2: ...cos you don't get that in everybody. Some people *pretend* they're listening...

R: Mm-hmm.

P2: ...and at the same time they're thinking, 'Oh God, I wish she'd hurry up'.

P2: And I feel that I can really *open up*...

R: Ok.

P2: ...and that I'm being *listened* to.

P2: ...it's nice to know that someone is really listening to you.

P2: ...you've brought out everything in me...

R: Ok.

P2: ...that I wanted to say, and I've said it...

R: Ok.

P2: ...and you've *listened*.

R: Ok.

P2: That's the most important part when you *listen*.

It's clear that being listened to is very important to both Patient 1 and Patient 2. The theme appears to be one of setting the researcher apart from other people who don't listen, but *pretend* to do so. These patients are letting me know that they perceive our rapport positively and that my listening is being noticed. It sounds like Patient 2 is saying that the fact that I'm listening is facilitating her openness with me. I need to keep an eye out for this theme elsewhere in these interviews and in future interviews, and tune in to other aspects of our rapport as they come up.

Figure 4: Memo – Being Listened To

B. Focused Coding

The researcher next engaged in focused coding, which moved the analysis into a more theoretical phase. This process involved identifying the most salient codes from the initial coding and deciding which of these appeared to categorise the data best (Charmaz, 2006). Focused coding allowed the researcher to elucidate bigger blocks of data, whilst categories were further refined and comparisons between blocks of data continued.

C. Axial Coding

The next stage of analysis comprised of axial coding. Having fragmented the data during the initial coding phase, this next stage involved bringing the data back together in a fresh way. This was achieved by linking categories to sub-categories and identifying dimensions and properties of these categories (Charmaz, 2006). This helped to further decipher and arrange the large quantity of data, thereby advancing the researcher's interpretation.

D. Selective Coding

Following Strauss and Corbin's (1998) guidelines, the researcher next moved to selecting the central category (i.e. the key emerging theme) in the data. This involved choosing the category/categories to which almost all cases pointed and around which other main categories could be organised. The researcher continued to refer to memos in order to extend and integrate her ideas, whilst developing her framework (Charmaz, 2006). In addition, the creation of diagrams aided this process.

E. Theoretical Saturation

Slow recruitment and time restraints prevented the researcher from continuing to collect data until theoretical saturation was achieved.

F. Writing This Report

As suggested by Charmaz (2005), data analysis continued whilst compiling this research report, as further ideas occurred to the researcher and extended her developing framework.

2.10 Ensuring Quality in Qualitative Research

Many researchers (e.g. Lacey & Luff, 2001; Smith, 2006; Willig, 2005) have discussed issues surrounding rigour in qualitative research. It has been argued that qualitative methods cannot be judged by the same appraisal methods (e.g. generalisability, reliability, replicability and validity) applied to quantitative research. Although disputes abound regarding the best criteria to apply to the evaluation of qualitative methods, there appears to be some agreement that the following criteria are important:

- ◆ Auditability;
- ◆ Credibility;
- ◆ Reflexivity; and
- ◆ Triangulation.

Auditability

Auditability refers to the extent to which the stages in a research study can be easily inspected (Rodgers & Cowles, 1993). From the beginning of the analysis, the researcher kept written notes, as well as memos in NVivo 7, to record her thoughts and observations regarding the data and emerging categories. This permitted her to track the decisions taken to advance her ideas whilst developing her framework and allowed for greater auditability of the study. All transcripts of research interviews and associated memos are available for review upon request.

Credibility

According to Lacey and Luff (2001), the validity of a qualitative study is evaluated by the extent to which the data substantiate the interpretations made. Charmaz (2006) referred to this as the *credibility* of a study. To enhance credibility, the researcher has incorporated quotations into the results in order to demonstrate the relationship between the data and her interpretations.

Respondent validation (i.e. gaining the views of research participants on preliminary interpretations of the data) has been posited as another means by which to enhance a study's credibility (Lacey & Luff, 2001). It was not ethically possible to involve the research participants in such a process, as most patients had deteriorated significantly by the time preliminary results were available and all except one had died by the time the final results were compiled.

Reflexivity

Smith (2006), amongst others (e.g. Burck, 2005; Charmaz, 2006; Parker, 2005), has highlighted the importance of reflexivity in augmenting the credibility of qualitative research. Alluding to the work of West (1994), Smith (2006) defined reflexivity as ‘the extent to which individuals can reflect upon themselves and modify their actions and thought processes accordingly’ (p.210). She advocated the inclusion in qualitative research reports of examples of self-reflection, which have contributed to learning and shaped one’s research. She asserted that such inclusion could provide the reader with invaluable insights into the researcher’s perspectives. However, Parker (2005) warned that examples of reflexivity must not be excessive and should be used only when they provide valuable information to the reader.

Recognising the importance of reflexivity, the researcher compiled memos and kept a reflective diary (recommended by Burck, 2005) throughout the research process. Regular meetings with her supervisors also provided the researcher with an essential space within which to address issues arising throughout the data collection and analysis phases, further enhancing her reflexivity. Consistent with the advice of both Smith (2006) and Parker (2005), the researcher has endeavoured to provide pertinent examples of her reflexivity throughout this report. Excerpts from her reflective diary during the DPQP and ISS, respectively are included in Figure 5 overleaf.

Patient 2 – Draft Review Meeting – Private Room At Hospice

This was a very moving experience for me, as it appeared to be for the patient, in a very positive way. Reading back the patient's words to them was a very powerful process and it was nice (and a relief) to know that the patient was very happy with their interviews! Bringing up the bits to be edited was totally fine and the patient expressed their understanding and acceptance of the potential harm, should the words be included. Accordingly, we edited out a significant portion of the text and agreed on preferred and minimal wording. This meeting felt very rewarding. I look forward to giving the patient their final copy! It's been a real pleasure spending time with them.

Patient 7 – Research Interview (ISS) – At Patient's Home

Today's interview felt like it went really well. Although short, it felt very unrushed and that the patient got to say everything they wanted. They were mostly very positive about their experience of the process, despite having suggested at the start that it was unlikely to help them personally. They found it a very positive thing to have their own words documented, incorporating the important messages they wanted to leave for their children once they were gone. I felt that I had been involved in a very important and special process with them...

Figure 5: Excerpts from the Researcher's Reflective Diary

Triangulation

Triangulation is an additional method considered to show rigour in qualitative research. It involves collecting or analysing data from more than one source (Lacey & Luff, 2001). Although data in this study were collected by one researcher from one source (i.e. patients) only, data analysis incorporated multiple perspectives. The researcher's interpretations of interview transcripts were compared with those of her academic and clinical supervisors, respectively, both of whom have different expertise, in a process known as *investigator triangulation* (Jamieson *et al.*, 2007).

Whilst this process mainly supported the researcher's hunches regarding emerging categories, it also frequently introduced her to additional or alternative interpretations of the data. Accordingly, this served as a useful check on the credibility of the evolving findings.

Figure 6 overleaf summarises the key analytic stages of the grounded theory approach adopted in this study, alongside the means by which the research quality was addressed.

2.11 Dissemination of Research Results

The researcher sent a results summary (See Appendix 15) to the only surviving patient, who had expressed their wish for a copy. These findings will also be presented to the clinical team at the hospice, as well as to other interested and relevant palliative care professionals at the earliest opportunity.

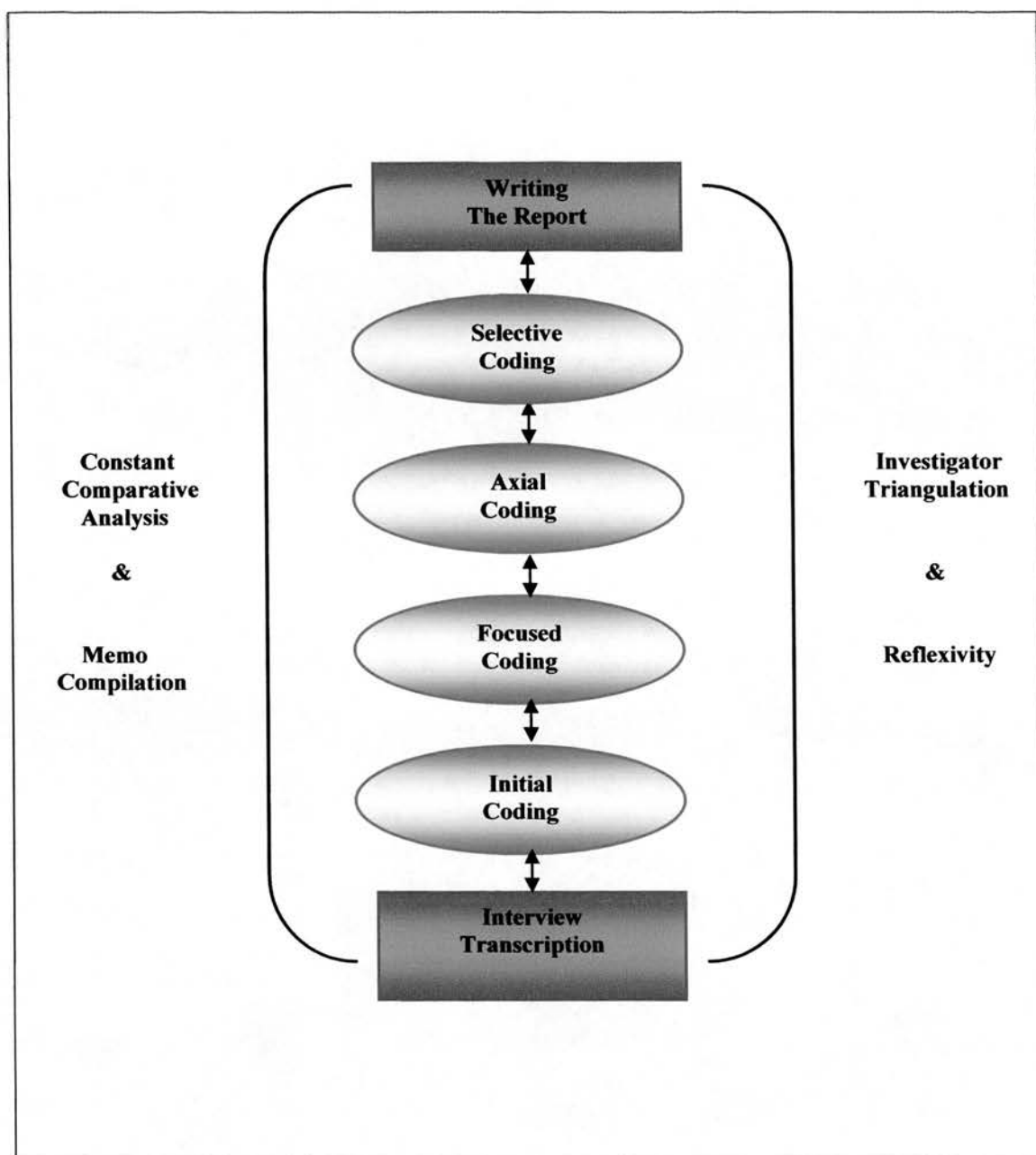


Figure 6: An Overview of the Analytic Steps Undertaken in This Study

3.RESULTS

This chapter describes the study participants, the duration and timing of participation, and the journal recipients. The qualitative findings are presented here and will be discussed fully in the subsequent Discussion chapter.

3.1 Participant Information

Eight patients (six inpatients and two outpatients) took part in this study. Participants comprised of one male and seven females, ranging in age from 50 to 87 years (mean 73.38, SD 11.78). Primary diagnoses included metastatic breast cancer, metastatic carcinoma of the rectum, metastatic colonic carcinoma, metastatic lung cancer, pancreatic cancer and motor neurone disease. The approximate length of time from patients' primary diagnoses to recruitment, based on occasionally unclear records, ranged from 3 months to 12 years (mean 42.25 months; median 24 months; SD 48.03). Six patients were Scottish, one was Indian and one was Irish. Two patients were single, two were married and four were widowed. Five patients were Protestant, two were Catholic and one was Muslim. The highest level of education of five patients was secondary school, whilst a further three patients had progressed to third-level education. Table 1 overleaf presents patients' demographic details and their distribution. Due to the need to ensure anonymity, the researcher is unable to provide patient-by-patient descriptions.

Table 1: Demographic Characteristics of Patients (N=8)

	N
<u>Patient Status</u>	
Inpatient	6
Outpatient	2
<u>Gender</u>	
Male	1
Female	7
<u>Age</u>	
50-59	1
60-69	1
70-79	3
80-89	3
<u>Primary Diagnosis</u>	
Metastatic breast cancer	3
Metastatic carcinoma of the rectum	1
Metastatic colonic carcinoma	1
Metastatic lung cancer	1
Pancreatic cancer	1
Motor neurone disease	1
<u>Time Between Primary Diagnosis & Recruitment</u>	
0-6 months	1
7-12 months	2
1-5 years	3
6-10 years	1
>10 years	1
<u>Nationality</u>	
Indian	1
Irish	1
Scottish	6
<u>Marital Status</u>	
Single	2
Married	2
Widowed	4
<u>Religious Affiliation</u>	
Catholic	2
Protestant	5
Muslim	1
<u>Highest Level of Education</u>	
Secondary School	5
Third-Level Education	3

3.2 Duration of Participation

Completion of the DPQP required between 1 and 3 sessions (mean 1.88; SD 0.83). The combined duration of these sessions ranged from 29.43 to 149.07 minutes (mean 67.39; SD 38.55). Subsequent Draft Review Meetings were not timed, but were limited to one hour. Research interviews following the intervention ranged from 15.20 to 42.28 minutes (mean 26.73; SD 9.16). Total patient contacts ranged from 3 to 5 (mean 3.63; SD 0.92) and total days over which contacts were spread ranged from 4 to 42 days (mean 22.75; SD 12.31). Table 2 overleaf presents this information.

3.3 Days Between Participation and Death

Seven participants had died by the time this report was complete. The length of time from the beginning of a patient's participation to their death ranged from 16 to 201 days (mean 98.86; median 79; SD 63.28). The length of time from the end of a patient's participation to their death ranged from 12 to 159 days (mean 77.29; median 61; SD 55.12), as shown in Table 2.

Table 2 – Duration of Participation & Days Between Participation and Death

Patient	No. of DPQP ^o Sessions	Total Length of DPQP (Minutes)	Draft Review Meeting	Length of Research Interview (Minutes)	Total Patient Contacts	Total Days Over Which Contacts Were Spread	Days Between Participation & Death
1	2	91.20	No*	33.42	3	14	114
2	3	149.07	Yes	42.28	5	42	159
3	2	67.95	Yes	32.20	4	28	118
4	3	63.68	Yes	26.45	5	31	16
5	2	54.78	Yes	15.20	3	18	61
6	1	51.73	Yes	27.28	3	14	61
7	1	31.28	Yes	17.67	3	31	N/A [^]
8	1	29.43	Yes	19.30	3	4	12

^o DPQP: Dignity Psychotherapy Question Protocol

* No Draft Review Meeting as this patient did not request a journal

[^] N/A: Not Applicable

3.4 Journal Recipients

Seven patients requested journals following the DPQP, with the numbers requested ranging from 1 to 8 copies (mean 3.25; SD 2.60). One patient sought a journal solely for themselves, two patients requested journals exclusively for family members, whilst a further four patients sought copies for both themselves and family members. Journal recipients included spouses, children, daughter-in-law, siblings, nieces, nephews and grandchildren. No patients requested a journal for somebody out with their family.

3.5 Qualitative Findings

3.5.1 Overview of Patients' Perceptions of Dignity Therapy

The key aim of this research was to ascertain patients' perceptions of the intervention. Analysis of patients' narratives resulted in the identification of two core categories, namely 'Rapport' and 'Therapy'. Furthermore, the analysis suggested a relationship between these categories – that is, that the rapport between the patient and the researcher facilitated the therapeutic encounter for patients. This relationship, which will be discussed in greater detail later in this report, forms the basis of the developing framework illustrated in Figure 7 below.

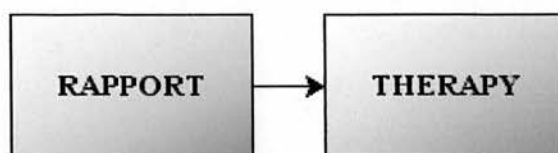


Figure 7 - Relationship Between Core Categories Rapport & Therapy.

These core categories and their subcategories will be discussed separately and illustrated by excerpts from patients' transcripts in order to demonstrate the data leading to these findings. Quotations presented in bold, italic font represent those of the researcher, whilst excerpts in regular, italic font represent patients' dialogues. Words that were emphasised by either speaker are underlined.

Core Category: Rapport

The term 'rapport' is used to represent patients' descriptions of the positive relationship they perceived with the researcher throughout the intervention. Rapport is discussed within the context of the following two sub-categories:

- ◆ Listening
- ◆ Compassion

These sub-categories are depicted in Figure 8 below.

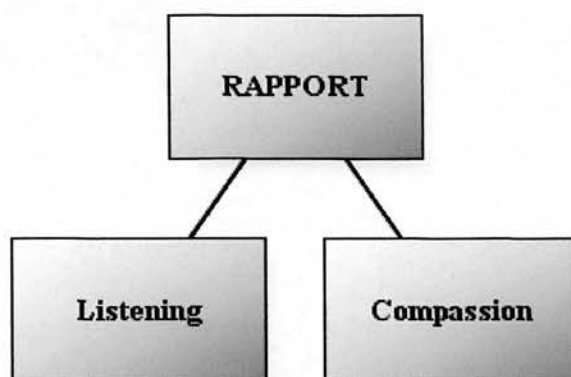


Figure 8 - Core Category Rapport & Related Sub-Categories.

Sub-Category: Listening

The term 'listening' was chosen to reflect patients' repeated references to the researcher's undivided attention, and their appreciation of it, during the intervention.

The quotations below illustrate this theme:

In what way do you think that's [telling me about your life] helped you?

Well...you're talking to somebody who's listening, you know. (Patient 1)

Thank you for listening to me. (Patient 1)

It's nice to know that someone is really listening to you. (Patient 2)

I don't know how...to express myself properly, but I feel that at last somebody's listening to me. (Patient 2)

You've brought out everything in me...that I wanted to say, and I've said it...and you've listened...That's the most important part when you listen. (Patient 2)

It's [the intervention] really, really helpful and good.

Do you want to say a wee bit more?

...Sharing my problems with somebody else and them listening to me. (Patient 3)

I'm wondering what comes to your mind when you say, 'It's been great'.

Just being able to tell ya and then listening to me. (Patient 3)

Two patients contrasted this to being with others whom they perceive as not listening:

Not like eh, a lot of people talk to other people and...they don't take in what the person is saying you know...You know when they're not listening, when they're just saying, 'Yeah, yeah' you know [laughs]! (Patient 1)

I know within my heart that I can open up and it's just you and...that's a big help... 'cause you don't get that in everybody. Some people pretend they're listening...and at the same time they're thinking, 'Oh God, I wish she'd hurry up.' (Patient 2)

To know that you're not in your mind saying, 'Aw, true life couldn't have been like that'... You are listening to me. (Patient 2)

In keeping with this, one patient highlighted the importance of listening when choosing one's conversation partner:

I'm not saying everybody's not listening you know...It's just when you think that they're not listening you know, you're gonna want to talk to somebody else you know! [laughs] (Patient 1)

Another patient mentioned that the opportunity to have somebody listen to them was especially important, given that they had nobody to whom they could speak openly. Although they were aware that their family were available for them, they seemed to wish to protect their family from the distress that their words might evoke:

That [getting things off my chest] was helpful...because I didnae have anybody to confide in. You cannae keep saying it to your family. You upset them and there was really naebody to listen...where you were at [laughs] the other end taking it all! (Patient 3)

A further patient reflected upon the researcher's attentive manner in the context of the extended age-difference between the two. In doing so, they relayed their perception that older people are often over-looked by younger people, as shown in the quotes overleaf.

Because how many nice-looking girls like yourself want to listen to old fogies like myself? (Patient 2)

You listen to us and believe in us...and that matters, because believe it or not, when you get older, I think that they [younger people] think that you're passed it and that you're gone...not mental, but a bit... soft in the head and we're not! (Patient 2)

Considered collectively, these extracts demonstrate patients' appreciation of the researcher's attentiveness to their narrative, in a world where accessible others, for whatever reason, often do not seem to listen or may not be perceived by the patient as the best individuals to whom to speak.

Sub-Category: Compassion

The term 'compassion' encapsulates patients' references to feeling cared for by the researcher. Whilst some patients' remarks pinpointed clearly these positive characteristics of the research relationship, other comments were occasionally less clear-cut. However, within the context of the narratives, these latter remarks were interpreted by the researcher to signify compassion. The following excerpts reflect this theme:

Even sitting there talking to me, you give me...a feeling of kindness, caring and wanted. (Patient 2)

I see you're even going through what I've gone through in your mind. (Patient 2)

I mean there's not many people like yourself that does things like that for people like me...that they can say what they feel and it's not gonna be thrown in their face. (Patient 2)

Well, about how you talk to me an' all that, an' the help that I've had an' I dae ken hen, just you were there. (Patient 3)

Two patients also mentioned that the researcher's manner had instilled confidence in them.

Everything you've done and said, you've given me confidence. (Patient 2)

It [the editing process] gave me confidence...to go on and do the rest and helpful... 'cause it's the way you ask them [the questions].

What way did I ask them?!

I don't know...but you did it properly! (Patient 5)

As in the case of listening, the issue of age was raised in relation to the compassion perceived within the research relationship.

You said to me that the fact that I was young made a difference to the process.

Yes. It's lovely...

How did it make a difference?

Because it's nice to know that if you're caring just now, as years go on, you're gonna become more caring, more caring and em...you're the person that you are...

If I was older doing these interviews with you, if I was an older lady, would that have made any difference to the process?

No, if they thought the same as you do. (Patient 2)

The importance of the researcher's manner as early as, and even before, she met participants, was highlighted in the following quotes:

When they [family] read it [Letter 1], they saw what I'm seeing in you...They haven't met you, but just by reading your letter, they...saw the sincerity of it. (Patient 2)

Because when I first met you, if you had come across that em, yes you would be doing it, but there wasn't the warmth or what I really wanted, I would likely have said, I'm afraid I can't go through with this. (Patient 2)

Alongside these excerpts, the ensuing quotations encapsulate the importance of compassion in any patient-professional relationship:

It's just like when you go to see a consultant or a surgeon, you can get one that loses out...feelings...You are someone...but they can be the top surgeon or the top consultant, but if they're treating you, yes they're the best, but if that warmth doesn't come through to you...you never go to the operating table or for treatment the way you would go for a consultant or a surgeon that shows a bit of humanity...and em... they're seeing you as a real person...and you see them as a real person. (Patient 2)

That [the rapport] is very important. If you haven't got that, you've no story. (Patient 2)

Overall, these quotations suggest that several patients perceived the researcher as displaying compassion in her interactions with them. It is contended that this affirmative bond perceived by patients facilitated their participation in both dignity therapy and the research interview which followed. Although other aspects of the rapport, such as collaboration and respect, were also mentioned by patients, there were not enough data to substantiate these facets of the patient-researcher relationship as themes.

Core Category: Therapy

The term ‘therapy’ summarises the different components of the dignity therapy intervention as identified by patients. This category, which is depicted in Figure 9 overleaf, is discussed via four sub-categories:

- ◆ Looking Back
- ◆ Sharing Memories
- ◆ Getting Things off Their Chest
- ◆ Putting Their Story on Paper

‘Putting their story on paper’ is divided into two further themes, which include:

- ◆ Making a Book
- ◆ Editing the Words

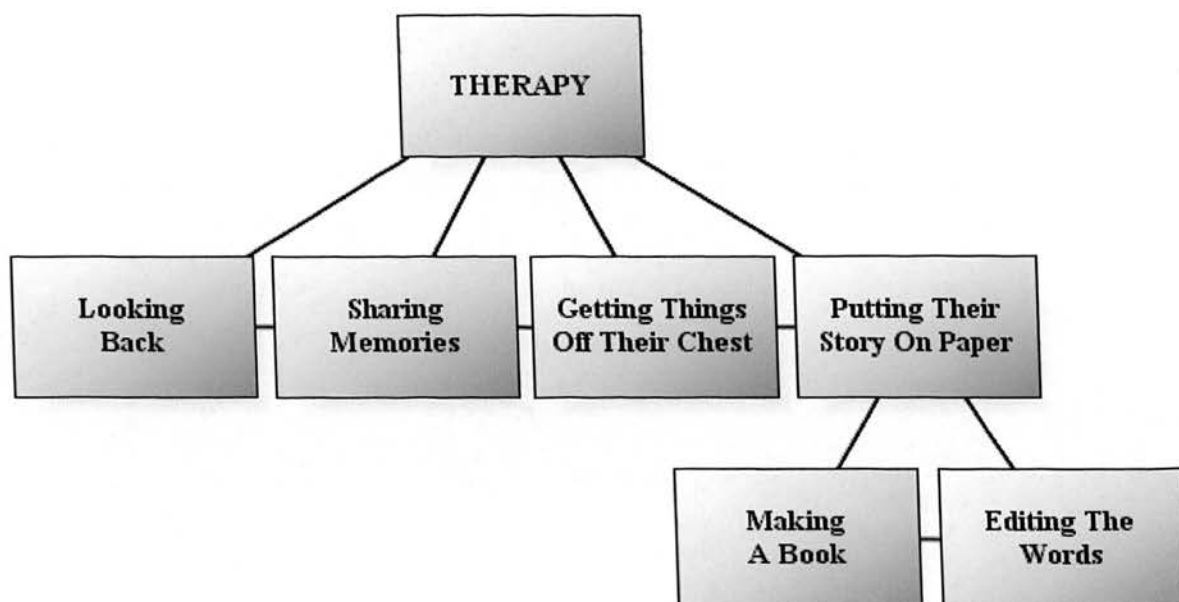


Figure 9 - Core Category Therapy & Related Sub-Categories.

Sub-Category: Looking Back

The expression ‘looking back’ encapsulates patients’ descriptions of having found it helpful to look back over their lives whilst undertaking the intervention. The following quotations echo this theme:

Anything else you want to say about what was helpful for you about going through that [dignity therapy]?

Well, going back and all the memories [laughs]! (Patient 3)

I found the whole process very helpful. It made me just look back. (Patient 4)

I think it didn’t do me any harm to look back and look back how I loved my life. (Patient 4)

It was interesting to go back over the years and remember what happened when...silly things as well as good things [laughs]! Silly things as well as sad things [laughs]! (Patient 5)

Well, I just think it was helpful to make you stop and think about yourself...and what you had done... (Patient 5)

Three patients specifically mentioned the significance of reviewing happy times whilst looking back:

It made you look back on these things in life and sometimes you mightn't look back on those...and pick out the happy times. (Patient 4)

It brings back all the happy times and makes you forget the miseries [laughs]!

How did it make you forget the miseries?

Well...the happy times are more important...and you realise...there were more of them. (Patient 5)

Do you have particular types of people in mind when you say, 'the ones that need it most'?

Well, I think it's some of the ones that are so depressed about now that they can't think back and think of how fun it's been in life... 'cause they must have...some happy memories...but all they see is this bleak future in front. (Patient 6)

Similar to the preceding excerpt, another patient suggested that although looking back over one's life is important, people might not reflect upon their life when seriously ill or actively avoid doing so:

I think that it's [looking back] what a lot of people don't do...They're moaning and groaning about the wall they've come up against, because it is a big, big wall.

When you say, 'the wall they've come up against'...

Against their cancer...their illness or whatever. They don't or they don't want to look back...You know, people don't and I think we should. (Patient 4)

Consequently, the reflective component of the intervention was perceived by this patient as well-timed, given that they were ill:

I was in a position where I should look back...you know, at my life. I think we all should have a quick glance back every so often at maybe what we're doing.

What did you mean there by 'I was in a position where I should look back'?

Well, I was ill. (Patient 4)

Some patients mentioned that looking back had induced positive feelings for them.

For one patient, this process had brought about a sense of calm:

I had to go over it all and it made me just calm about everything that had happened. (Patient 5)

Two patients mentioned that looking back over their lives had made them feel fortunate:

Well, I realise now I've had a very good life...and I've been very lucky and I've been well enough to have done all that sort of thing...I had to go over it all and it made me...realise how lucky I've been. (Patient 5)

Yes, I think in a way it made me realise just how much I had in the early days, dependent on mother doing everything...We just took it as girls for granted that...the washing and ironing was done...You had a hot meal ready...That was normal. (Patient 6)

One patient also alluded to finding it interesting to review their life:

It was interesting to go back over the years and remember what happened when...silly things as well as good things [laughs], silly things as well as sad things [laughs]! (Patient 5)

Overall, these quotations suggest that many patients valued the opportunity to look back over their lives during the intervention.

Sub-Category: Sharing Memories

The term 'sharing memories' reflects several patients' reports of having appreciated the opportunity afforded by dignity therapy to share their life story. For some patients, sharing their history involved providing a general account, whilst for others, this involved delving into both happy and painful memories. Based on patients' narratives, sharing memories appeared to be particularly constructive, rather than simply reflecting on their past on their own. The following quotations exemplify this theme:

What, if anything, did you find helpful about the process?

Well...letting you know about my past life...letting people, somebody else know...how you lived and that. (Patient 1)

It's good to be able to talk about it [my life]. You feel uplifted. (Patient 2)

Anything else you want to say about what was helpful for you about going through that?

Well, going back and all the memories [laughs]! I mean, they're always there...You have them in there, but you're not sharing them...

You're pointing to your heart there.

Aye...I feel as if I've shared them. (Patient 3)

Was there anything else about the process at all that was helpful in any way for you?

It made my brain work...to take you back and give you dates and give you things that have happened... 'cause...that's something that sort of fades into...insignificance... (Patient 5)

For one patient, sharing their history had led them to ascertain coherence in their story and to discover a theme within it:

I found it [the intervention], in a way it was interesting, because I had never actually put them all together...I've had each section [of my life] separate...and...I then saw the thread running through it all. (Patient 6)

As regards discussing more painful memories, two patients suggested that these were ever-present, but only occasionally, if ever, shared:

Given then that these memories have brought up those [negative] thoughts...
Yes, they bring them up, but they never leave you...You put them at the back of your mind...and you close the door. Occasionally the door opens. (Patient 2)

I mean, they're [the memories] always there...You have them in there, but you're not sharing them. (Patient 3)

Whilst one patient mentioned having mixed feelings regarding sharing these memories, another patient appeared to accept such memories, and talking about them, as a fact of life:

Though I've been telling you...you're sort of re-living it too...and you see the bad side of people and the good side of people.

So has re-living it been a positive thing or a negative thing, or maybe both?

I think both...because you can't forget the physical pain either.

Has anything been unhelpful for you about that [re-living difficult memories]?

No, it's helped me really...because sometimes it's good to remember too, 'cause it makes you analyse more things and you try to think, 'But why were they like that?'
(Patient 2)

What was it like for you talking about the negative experiences or the sadder...?

Ach, that's just life hen...just part of life. (Patient 3)

Just as some patients had set the researcher's listening apart from others', two patients' remarks suggested that the researcher would value their narratives more than seemingly disinterested or disbelieving individuals. The reasons for this are unclear, although the rapport and the therapeutic context of the discussion perhaps led patients to perceive this.

Yeah, well everybody talks about their life to other, bore people to death you know with their life...but you get more out of it than a lot of other people would you know.
(Patient 1)

I think it [dignity therapy] would help people, because often when you've gone through what I've gone through, people will say, 'Aw, that can't be true! That doesn't go on in this age', but they've got a lot to learn from life...

So you feel that being able to say what you've gone through has been helpful?

Yes. Yes. Yes...very much so. (Patient 2)

The absence of a confidante in one patient's life made the opportunity to share their memories especially significant:

Do any particular questions stand out in your mind that were helpful?

Just asking me about the family and explaining things, and telling you about my happy times and the sad times...and that is important too, when you're on your own and not got a husband an' that. (Patient 3)

Taken together, these excerpts suggest that several patients welcomed the chance to share their memories during dignity therapy and found it helpful to do so.

Sub-Category: Getting Things off Their Chest

The phrase 'getting things off their chest' captures several patients' descriptions of having found it helpful during dignity therapy to express feelings and thoughts that have typically, but not always, remained unarticulated. This process appeared to be

distinct from simply sharing memories and instead to reflect the disclosure of patients' *current* concerns (e.g. their diagnosis, funeral plans, unresolved family issues or future hopes for loved ones) about which patients were thinking or struggling. Whilst some comments may appear to the reader to be relevant to the previous sub-category, 'sharing memories', within the context of the intervention interviews (the content of which remains private and is not reported here) and the research interviews, these remarks were perceived by the researcher to signify patients' appreciation of the chance to get present troubles off their chest. The excerpts below and overleaf reflect this theme:

Well, the course of our contact has been wonderful...I've opened up my heart and I've said everything that's been lying there. (Patient 2)

I've got it all off my chest. (Patient 2)

It's [dignity therapy] really, really helpful and good...You're bringing out things that you cannae bring out normally and sharing them with you. (Patient 3)

You said to me at the start that you would recommend this process.

Well I would... 'cause you get things oot that you keep all bottled up an' you do. (Patient 3)

There's a lot you have to say and if they come oot, you feel a lot, lot better. (Patient 3)

Even that means that gives them an emotional, you know like a lid, that you can lift up and release the pressure...that they may not be able to do...on a daily basis, so that might give them a chance...a vent...a vent to their feelings. (Patient 7)

What was it like for you going through this process?

Eh, it was like, well I'm not saying lifting a load off my mind, but it's like knowing that I've done something, that I've not just left it untold or unsaid. (Patient 8)

Some patients cited positive emotions on account of getting things off their chest during the intervention. For example, two patients spoke of feeling calm, as reflected in the following quotes:

Because there's a lot of people too, they've no-one to talk to about it and then if they're given the chance to say what's really in their heart and it gives you like peace inside you...

Have I got it right that you feel it's given you peace inside you?

Yes, yes. (Patient 2)

Sharing my problems with somebody else and them listening to me...because...my mind was quite troubled...I couldnae sleep for thinking about things and now I shut my eyes [laughs] and I sleep!

So now the things that were in your mind...

That were in my mind are out...and they're on paper...and I feel calm, a lot calmer...I mean, maybe I look calm and everything [laughs] on the outside, but inside sometimes it's a turmoil. (Patient 3)

A sense of pride was also attributed by one patient to having opened up during the intervention:

Just proud of being able to say how I feel an' ...how I've been treated, an' the care that I've had. (Patient 3)

Two patients also alluded to a sense of relief as a result of getting things off their chest:

I've opened up my heart and I've said everything that's been lying there and it's been a relief to get it out. (Patient 2)

Like a weight off your mind. (Patient 3)

The issue of timing re-emerged regarding getting things off one's chest, with some patients' comments suggesting appreciation of the timing of this aspect of the intervention:

Well, especially we all know when we're coming here that this is the last road...and I think it does you good to get this all off [gestures to her chest]... (Patient 2)

I don't think it does anybody any harm and I think when you've got to hospice stage...you know, things should be talked about. (Patient 4)

I feel they [family] should know if it's family business...because they're [the patients] not gonna be here all the time. (Patient 8)

One patient repeatedly referred to the marked differences in Scotland and America as regards the open discussion of difficult issues, such as cancer:

I think you know, unlike Americans, we...The Americans talk so openly about, eh, it [cancer]...It's just so different, isn't it? (Patient 4)

You see I don't think eh, generally across Scotland or generally in Scotland, that...we talk enough openly about cancer or these things. (Patient 4)

The cultural context of the intervention may perhaps also be illustrated by the remarks of another patient regarding people's inhibitions expressing their feelings:

So you said to me there, people keep it [their feelings] to themselves all their lives. Do you want to say a wee bit more?

They dinnae want to say they love this one and they love that one...but love's a wonderful thing. (Patient 3)

You've said to me that people keep it to themselves...all their life.
They do. People dinnae talk, dinnae communicate. (Patient 3)

Considering these extracts collectively, it seems that many patients found it helpful having the opportunity to get things off their chest during dignity therapy.

Sub-Category: Putting Their Story on Paper

The phrase ‘putting their story on paper’ reflects patients’ comments regarding the value of (a) ‘making a book’ and (b) ‘editing the words’ during dignity therapy. In the case of ‘making a book’, patients spoke of benefits for both themselves and family. These are discussed separately below.

a) Making a Book

Impact on Patient of Making a Book

The quotations below exemplify the positive reactions of many patients to the opportunity afforded by dignity therapy to make a book/journal about their life and the important messages they wished to pass on.

It was a laugh. I always says, ‘I’m gonna write a story of my life...It’ll be a best-seller [laughs]!’ (Patient 3)

It’s really good to see it down, to read it again. (Patient 3)

It’s quite nice to see it in black and white...because...as I say, you don’t often get a chance. (Patient 7)

It gives the person a chance to speak and to be documented in black and white...so whenever a person wants to think about me and read the journal...so although I’m not there to say it, it’s like a book. (Patient 7)

Some patients reported positive feelings as a result of having made a book. One patient spoke of feeling lucky that they had had the chance to document their important messages for their family:

Reiterating the fact that I have made it [the journal] telling them and then hearing them [my words] again and again just made me think, 'Yeah, I am lucky that I have told them what I should have...rather than some people not making it'. (Patient 7)

Another patient alluded to a sense of optimism as a result of making a journal:

I think the journal has brought that out too, the fact that I have a lot out there still to live for. (Patient 4)

Two patients also reported feeling proud regarding their journal, as shown in the excerpts below. For one patient, this sense of pride was linked to the perceived help their journal would provide to others, who might be experiencing similar difficulties. For another patient, feeling proud related to the personal significance of the document.

I'm the type of person that if I think for a minute that it's [the journal] gonna help somebody else, it makes me feel proud...feels as if my chest is expanding that...I've done something...I've achieved something. (Patient 2)

I feel that anybody reading this, or trying in their mind to experience what I've gone through, maybe they're having a bad time, maybe a little different, but in the long run, it comes to, on the same road...you know, and they'll say, 'Well if she can cope, so can I'. (Patient 2)

I'm quite proud of it [the journal]...I am...because it's me and my family an' all that. It's about me. (Patient 3)

Two patients attributed further positive emotions to reading their journal:

Aw God, it was quite emotional [laughs] really readin' it [the journal]!...It was nice reading all the wee things [laughs]!

Was that a positive experience do you think or, or a negative emotional experience?

No, I think that was pretty positive [laughs]! (Patient 3)

I just felt a wee bit eh, a bit of pleasure out of it [the journal]...and actually seeing it, which... is nice. It's nice. (Patient 8)

I'm very pleased with this [the journal]. (Patient 8)

The issue of timing arose once again, with one patient endorsing the timing of this aspect of dignity therapy with regard to their own circumstances:

For me personally, I think it is the right time...while I've still got my speech...to do it. Don't know what future holds, but that was fine. So the kids are old enough now to understand, 'cause if they were little, they probably would not understand the emotional...side of it, but now they're mature, I think they can probably understand a bit more. (Patient 7)

Unlike the majority of patients however, the process of making a book felt less momentous for one patient, who had repeatedly seen their words on paper throughout their career.

I'm too used to it to be surprised. I mean...I give say a speech or a conference or something...I get it written up, check it for mistakes...but most people might be quite surprised, 'Oh look, that's me!' (Patient 6)

Potential Benefits for Family of Making a Book

Some patients mentioned potential benefits for family as a result of having made a book. For one patient, the journal could provide both a source of comfort for family, as well as a means by which unacquainted others (e.g. their children's future partners) could get to know them after they were gone. The quotations below illustrate these perceived benefits.

If it is documented, it's always there...for people to read when they miss you or they want to think about you. (Patient 7)

You can pick it up and read it whenever you want...see if that's any comfort and it might give them that comfort they're looking for. It might bring a smile on their face...or a tear in their eye. (Patient 7)

I think it's [the journal] quite a good thing to leave behind for people...who've not had a chance to know me, so that might give them an idea...as to what kind of a person I was. (Patient 7)

Another patient felt that their journal would inspire others:

People reading this, even if you're dead, they'll say, 'Oh, that lady's lived till she was 84 and she could cope with life like that...Well, there's hope for us all, all'. (Patient 2)

An additional patient spoke of the journal jogging the memory of their child, who had forgotten details of stories they had previously heard:

Well, [my child] said, 'Lots of things I know you've told me, but I've probably forgotten them...so it'll jog my memory too [laughs]! (Patient 5)

Of note, no patient cited potentially unhelpful consequences for family.

b) Editing the Words

This section presents quotations which illustrate several patients' comments regarding the usefulness of co-editing their words with the researcher during the Draft Review Meeting. For some individuals, the editing process provided an important second chance to add forgotten words to their journal, as reflected in the quotations below:

Sometimes you say things and miss out some things...and when you reflect back, you think, 'Oh, I should've added that.' That [the Draft Review Meeting] gives you a chance to correct it. (Patient 7)

Well, it [the editing] felt quite good, because I felt I coulda been missing something out, which I didn't do...with the help of you. (Patient 8)

The editing process additionally allowed patients to remove or to reword passages, which was appreciated by many patients who provided feedback about it:

That [the editing] was good, because I did babble on and I didnae think...I wasnae in it to hurt anybody...I just wanted them to understand. (Patient 3)

Was there anything unhelpful about the changes that we made to your journal?
No, not one bit and I'm glad you took it oot about the [child's private experiences], 'cause actually I never gave that a thought. (Patient 3)

I found it [the editing] very helpful, because I said there were [insensitive] things that you or I don't think about at all. (Patient 4)

That [the editing] was helpful too...because...you were very helpful in that bit...just helping me to get the right bits out. (Patient 5)

I think it's [the Draft Review Meeting] quite good...to reflect upon things, what you have said...and go back to it and add or deduct whatever you think you don't want to say. (Patient 7)

However, the process of editing felt less novel for one patient, who had repeatedly had their words within publications and speeches revised throughout their career:

It [the editing] wasn't a new experience...probably it would be to most people...but eh, I've been quite used...to that. (Patient 6)

For another patient, the emotionality induced by the researcher reading their draft journal to them during the Draft Review Meeting was perceived as somewhat unhelpful.

So you said to me there, 'It was quite emotional'.

Yes!...Just somebody else reading it out to me... 'cause when you say on a regular basis, you don't seem to realize...till you hear it from somebody else...the impact it has. (Patient 7)

What, if anything, did you find unhelpful about the process that we went through together)?

Mm, I don't think so. Sometimes it was a bit emotional...(Patient 7)

Looking at the collective quotes for both themes within this sub-category, it seems that most patients valued the chance to put their story on paper and to edit it with help, during the intervention. Although some quotations suggested that the journal could additionally benefit patients' families, the potential gains for family are less well substantiated.

Perceptions of Dignity Therapy as a Whole

Whilst the quotations hitherto presented allude to patients' perceptions of separate aspects of dignity therapy, additional comments were made in relation to the perception of the impact of the intervention as a whole. These perceptions are reflected in the excerpts below.

a) Positive Aspects of Dignity Therapy

Two patients talked of finding dignity therapy interesting:

I found the whole you know, process very interesting and I think that was...probably because I'm interested in that sort of thing. (Patient 4)

It was quite interesting, because it was different from any other I had done in the past, but it wasn't focusing on one particular thing that I had done...You were sort of taking the whole lot. (Patient 6)

Another patient referred to a sense of enhanced coping as a result of the intervention:

It makes you stronger inside...You can cope better. (Patient 2)

As well as mentioning feelings associated with the entire intervention, several patients alluded to the practical consequences of their participation. For one patient, simply informing their family about the research had resulted in family discussions, about which they were pleased:

Well I think it just helped... me in, in the fact that as a family you know...we started to talk about all these things again. (Patient 4)

Moreover, all patients' narratives suggested that patients felt glad that they had participated in the intervention. This interpretation is based on remarks, such as those presented in the extracts below:

Thank you for listening to me. (Patient 1)

What you've done is wonderful. It's just a pity there isn't more like you. (Patient 2)

It really was well done and it's a worthwhile thing to be able to do. (Patient 3)

I'm so delighted that the hospice is taking part. (Patient 4)

I think you're doing at the moment a fantastic bit of work. (Patient 4)

I'm glad you asked me to participate. (Patient 5)

Yes, well I quite enjoyed it, doing it, but just didn't see any help to me in it, but as I say, if I was helping other people then yes, I was glad to have done it. (Patient 6)

I am lucky that I have told them what I should have rather than some people not making it [the journal]. (Patient 7)

I'm very pleased with this [the journal]. (Patient 8)

b) Negative Aspects of Dignity Therapy

Two patients also identified unhelpful aspects of the process. For both, fatigue was cited as unhelpful, as illustrated by the following quotes:

I don't really think there was any [unhelpful aspects] you know, apart from you know, I suppose I got a bit tired and disgruntled. (Patient 4)

What, if anything, did you find unhelpful about the process that we went through together?

...Sometimes it was a bit emotional...and draining...just trying to put what you think into words. Sometimes that can be a bit draining. (Patient 7)

Consistent with these references to fatigue, one patient suggested that the intervention had been too long, a perception they attributed to the sudden, marked deterioration in their condition:

I found it quite long, but then I had the big hiccup in the middle. (Patient 4)

Also, like I was looking at them [the questions] through, well you know, I was tired...and I was you know, eh I probably wasn't well most of the time. These patients are going to be like that. (Patient 4)

This patient also suggested that other patients might not appreciate the length of the intervention:

You might get people who'll just say, 'Aw'...and make faces and a lot of people at the second interview will say, 'No, we don't want to do it'...

Why do you think that would be?

Well, I think...people don't like getting asked a whole lot of questions...and I think after they've had three, four questions they think you know, a lot of people'll think, 'Oh, oh that's it'. (Patient 4)

I think there was quite a lot on family...and like, I say that's fine. Maybe...it was more in our line, because...there were so many of us, we were interested in it...but there seemed to be quite a lot of kind of personal questions on you know, that line you know. (Patient 4)

Accordingly, they suggested that the process should be abbreviated for patients:

I think it should maybe be shortened slightly...for the ordinary patient. (Patient 4)

However, other patients' responses to queries regarding any unhelpful aspects of the intervention suggested that they perceived no negative features, as demonstrated in the following quotes:

Was there anything about it that you didn't find so helpful or that you would like to see different?

Not really, no. No. Not a, no. (Patient 1)

No. Everything's been helpful...Everything's been helpful. (Patient 2)

The only thing, I cannae answer that, 'cause nothing was unhelpful. (Patient 3)

I didn't find anything unhelpful about it. I thought the whole thing was very helpful. (Patient 5)

No. There was...nothing that bothered me at all. (Patient 6)

Not that I'm aware of hen, no. (Patient 8)

Considering the quotations above, in conjunction with those previously presented under the sub-categories of 'therapy', it seems that participants principally found the intervention to have beneficial consequences, although some negative aspects were identified.

3.5.2 Provisional Framework

Based on the findings presented, a provisional framework has been developed (see Figure 10). The framework suggests that the researcher's listening and compassion enhanced her rapport with patients and facilitated the intervention, which resulted predominantly in benefits for patients. Although patients' discussions of dignity

therapy suggested four somewhat independent components of the process (i.e. looking back, sharing memories, getting things off their chest and putting their story on paper), a close relationship appears to exist between them. The developing framework incorporates the idea that the value of the intervention for many patients was partly attributable to the combination of the components identified. However, this proposition is tentative and requires further substantiation, as do the findings regarding the potential benefits for family. Hence, the latter is represented by a dotted line in Figure 10 overleaf.

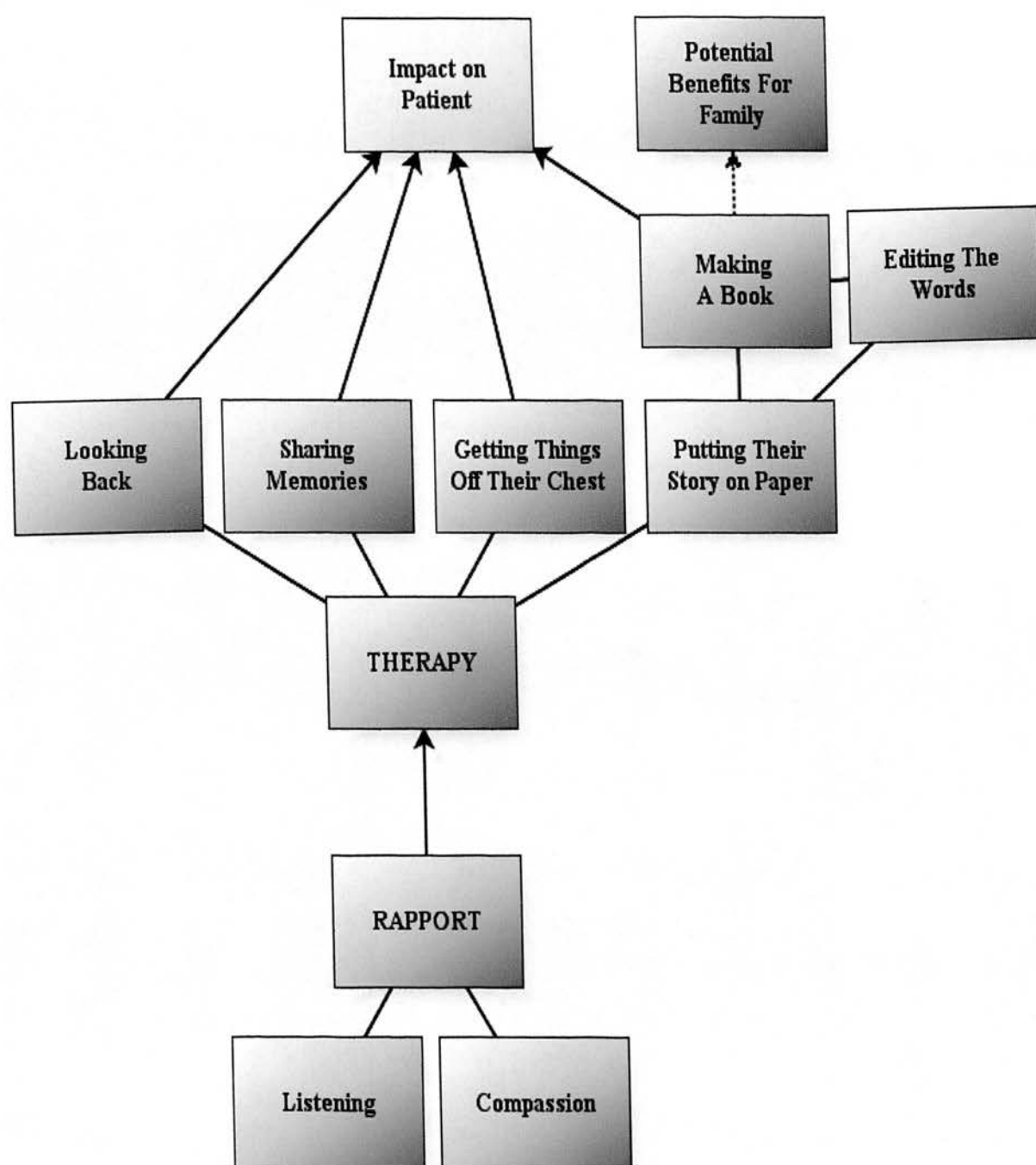


Figure 10 – Provisional Framework

3.5.3 Recommending Dignity Therapy

Another key aim of this study was to ascertain if, having undergone this intervention, patients would recommend it to fellow palliative care patients. When asked if they would recommend dignity therapy, seven of the eight participants stated that they would, as shown by the following excerpts:

Aw yeah. Anything that can help...other patients you know. (Patient 1)

Yeah. Aye, yeah. Anything's worthwhile trying you know. (Patient 1)

Yes, very much so. (Patient 2)

You've said to me so far that you feel that you would recommend this process to other patients in your position.

Yes...very much so...Yes...especially people in that position...to think that we're not forgotten. (Patient 2)

Definitely...It's really, really helpful and good. (Patient 3)

Yes. I think, yes. Yes, very much so. (Patient 4)

I think so...I think it would do them good...least specially the older people...Can't say that about young people, but even young people I'm sure it would help. (Patient 5)

I would've said [to other patients], 'Go ahead and do it'. (Patient 6)

Yes, I would. (Patient 7)

The final patient, who is not represented in the quotations above, appeared to misinterpret the researcher's enquiry regarding whether or not they would recommend the process. They seemed to perceive this as being asked if they would actively recruit others for it. Consequently, they expressed their view that patients needed to be left to make their own decision regarding participation.

It's entirely up to the person...I mean, if they don't want to, they don't want to. If they want to, they want to...and there's no way you're gonna change somebody no matter what I say, if I say, 'It was great. It's this, it's that'. (Patient 8)

Whilst recommending dignity therapy, some patients considered that it might not appeal to or be helpful to everybody:

If you can bring it to people that are listenin' to you, but you'll get ones that'll not, 'Oh no, I don't want to do it'. (Patient 3)

People don't like getting asked a whole lot of questions...and I think after they've had three, four questions they think, you know a lot of people'll think, 'Oh, oh that's it'. (Patient 4)

I mean some people nothing'll help...but I thought that just might help other people. (Patient 5)

Some of them might find it helpful. Others like me probably don't...because we've already in a way done it...I think some people would find it quite helpful and quite revealing. (Patient 6)

Two patients highlighted the fact that people have personally-defined disclosure boundaries which might impact decisions regarding participation.

Most of them are quite happy to talk about when they were young...It's when you get onto money and later things, but eh, most of them are quite happy to talk about their childhood...Well some of them just don't want you to know anything. (Patient 6)

I know that other patients may have things to hide and they don't want to let everybody know their business. (Patient 8)

Another patient mentioned that anticipatory anxiety might be an issue for some people:

What would you say to other patients about your experience of the process that we went through together?

Nothing at all to be afraid of. I mean so many people are terrified of the idea...but eh, tell them it's just quite simply...answering a few questions. (Patient 6)

When patients suggested individuals for whom dignity therapy might be appropriate, these ideas differed. One patient proposed that depressed patients might benefit from the intervention:

Do you have particular types of people in mind when you say 'the ones that need it most'?

Well, I think it's some of the ones that are so depressed about now that they can't think back and think of how fun it's been in life...but all they see is this bleak future in front. (Patient 6)

Two other patients suggested that inhibited individuals in particular might benefit from undertaking dignity therapy:

I think it would be lovely if you could get someone that is shy, that not backward but, they would love to come forward, don't know how...and it would be lovely to know what they're really thinking or how they can help somebody like themselves. (Patient 2)

It's quite a good thing for people who do not express themselves. (Patient 7)

Another patient cautioned that dignity therapy may not be appropriate for those below average intelligence:

We were intelligent. Like...I think you have to pick your patients carefully. (Patient 4)

You see, I don't think you know, the lower down the...scale you go, mentally go...I don't think some of these people could cope with a lot of the questions. I really don't. (Patient 4)

This patient also suggested that middle-class participants might be most suitable:

So if you were recommending who the process be for...who would you be recommending?

Kind of your middle class...person. (Patient 4)

Taken together, these excerpts indicate that the majority of patients would recommend dignity therapy to others, although they considered that it may not appeal to or be appropriate for everybody. There seemed to be no consensus regarding those for whom the intervention might be beneficial.

3.5.4 Feedback Regarding Journal Format

As the study progressed, the researcher was keen to ascertain how patients perceived the final document, which she had designed, in order to determine if it was fit for purpose. As shown in the ensuing quotations, patients seemed satisfied with the journal format.

It's [the journal layout] really quite professional. (Patient 3)

Is there anything that you would recommend be different about the layout or the way it's presented?

Everything was fine with me...I wouldnae change that for...anything...that you did. (Patient 3)

I think that [looking at the journal]...is a good way of doing it. (Patient 6)

It's good for reading, 'cause there's plenty of space and the questions and answers, you can see the different type...That's good. (Patient 6)

It's [the journal layout] plain and simple...nothing dramatic, 'cause I don't think it is meant to be like that. It's the message, rather than the layout, because it's not a product you want to sell...so you need to catch somebody's eye...so it's more to the point. That's what is more important...what's in it, rather than how it's been presented...so I think it's ok...acceptable...quite sombre...as one would expect...They don't want it to be very flashy...(Patient 7)

What did you make of the journal layout and the presentation of it, the way it looks?

I mean I think it stands out. There's just something that...stands out about it. (Patient 8)

I mean that...how it's broken down into...the light and the dark [font]... the small writing and the bigger writing...See, I'm not a reader...at all...but as I say, if I was picking that up...I wouldnae be put off by it. I would continue to read it. (Patient 8)

You made a good job [of the journal]. (Patient 8)

Of note, no patient, when asked, suggested improvements for the journal presentation. Consequently, it would appear that patients endorsed the researcher's journal design.

3.5.5 Home Interviews

As home interviews became necessary for four patients, the researcher was keen to find out how they perceived this context for dignity therapy. The narratives of those three patients asked about this issue suggested that they were supportive of home interviews for diverse reasons. One patient suggested that having the interviews at home was beneficial, given the minimal distractions:

I think it was probably easier here [at home], because you didn't have the distractions of nurses coming in and out and patients' visitors coming. I think it was easier with no distractions. (Patient 6)

Perhaps similarly, two patients also alluded to the enhanced privacy within their home environment:

You said to me it was easier to...go through the process in your home.

Yes, and I think most people would, because they wouldn't be frightened of someone else hearing. There's a fear... of anybody hearing your...business. (Patient 6)

I think it [a home interview] gives you that wee bit...freedom...to speak when and where. (Patient 7)

Another patient perceived that the home interviews were likely to have been more relaxing than they might have been if they had participated in the hospice:

What was it like for you taking part in this intervention in your home?

I think it's fine... 'cause it's your own environment...and you're more relaxed...at home, not under any pressure. (Patient 7)

A further patient seemed appreciative of the opportunity to share their world outside the hospice with the researcher, as shown in the quote overleaf.

The one in the home was good. It was nice to bring you into my home an' you see me in my own surroundings an' that...

So what was nice about that?

Well, just you [patient laughs heartily]!

In what way, what was nice about having the interview actually in your home and being seen in your own surroundings?

Ah well, now you've seen me in my own home. You knew where I came from an' that, not just a hospice. (Patient 3)

Based on the quotations presented, it appears that patients appreciated the option to participate in the intervention at home. However, it is acknowledged that these data are limited and require further substantiation regarding attitudes to home interviews.

3.5.6 Family Members' Reactions

When a patient mentioned their family members' reactions to the research in an early interview, the researcher became interested to learn how other patients' family had responded. Based on patients' narratives, it appears that three patients were completely open with family about their participation and what it entailed, whilst three others were selective about whom they told. A further patient told family about their participation, but limited what was revealed regarding the nature of the process. The remaining patient's communication with family was not established. Of those seven patients who mentioned having discussed the research with at least one family member(s), six described a supportive reaction, as portrayed in the following excerpts:

I'm so pleased to say, I discussed this with my [child] and [their partner], and they are a hundred per cent...behind me and yourself. (Patient 2)

Oh [child's name] is [aware of my participation]...[Child's name] thinks it's good. [My child] thinks it's a good thing. (Patient 3)

Like it definitely, as a family, we talked about it. You know, I wasn't doing it as a closed book, you know what I mean? We talked about it. (Patient 4)

Did they have any concerns about the research or you taking part?
None...none whatsoever. (Patient 4)

I spoke to my [child] about giving my [child] that [the journal]. I said, 'Would you be interested?' 'Very'...[Child's name] was very pleased about it. (Patient 5)

Do you think they [family] had any concerns about you taking part?
No, not really. (Patient 7)

[My child who I've told] thinks it's a good idea. (Patient 8)

Another patient mentioned that their sibling had reacted with humour to their participation:

My [sibling] said, 'I always knew that you needed your head seen to!' (Patient 6)

Some patients offered reasons, which were diverse, for the positive reaction of family members. One patient remarked that their family trusted their judgement regarding participation and accordingly, had no concerns:

Do you think they [family] had any concerns about you taking part?
No, not really, 'cause they know that it's always my choice...and they know that my judgment is quite good. (Patient 7)

Another patient mentioned that their family's familiarity with research had led them to be interested and to support their participation in the research, as shown in the quotations below:

They [family] thought it was super, but then they're people like...my [sibling] has taken part in...research...and my [other sibling] has taken part in research and my [sibling] in [overseas]... (Patient 4)

Well, they [the family] were very interested you see and we all kind of wondered what the next process would be. (Patient 4)

As mentioned previously in relation to the sub-category 'compassion', an additional patient suggested that the researcher's sincerity had been perceived by her family who had read the research invitation letter and that this had contributed to their positivity:

I don't know how to explain it. When they read it [Letter 1], they saw what I'm seeing in you...They haven't met you, but just by reading your letter, they...saw the sincerity of it...That's what it was...the sincerity. (Patient 2)

I haven't discussed a lot, 'cause I want them to read for themselves...so I'll see what they feel once I hand it over. (Patient 7)

Moreover, the researcher unintentionally met two adult children whose respective parents were participants in the study and both individuals thanked her for involving their loved ones in the intervention.

Overall, it seems that patients' participation was viewed positively by family members. However, the researcher acknowledges the potential pitfalls of relying on

participants to feedback regarding others' perceptions, as well as the possible selection bias regarding those who chose to participate in the research. These issues will be addressed when the findings are discussed in greater detail in the next chapter.

4.DISCUSSION

This chapter discusses the findings of this study in the context of previous research and suggests ideas for future research. It also addresses identified strengths and limitations of this study, considers the contribution of the findings and presents the researcher's reflections as a first-time researcher in palliative care.

4.1 Duration of Participation

Completion of the DPQP required between 1 and 3 sessions (mean 1.88; SD 0.83), with 5 of the 8 participants requiring two or more sessions to finish the question protocol. This contrasts somewhat from Passik *et al.*'s (2004) study, in which only one session was needed to complete the questions and Chochinov *et al.*'s (2005) study, in which most patients completed the protocol in one session and more sessions were only occasionally needed. In keeping with Chochinov *et al.*'s (2005) findings however, no patient in this research required more than three sessions to complete the DPQP. Therefore, the brevity of the intervention was upheld.

4.2 Days Between Participation and Death

The median survival from the end of participation to death in this study was 61 days, in contrast to a median survival of 40 days in Chochinov *et al.*'s (2005) research. The fact that the inclusion criteria in this study included patients with a life expectancy of <12 months, in contrast to Chochinov *et al.*'s (2005) cut-off of <6 months, perhaps explains this difference.

4.3 Psychological Distress

As addressed in section 2.1 of the Method, measures of psychological distress were not undertaken prior to or following the intervention. It was felt that a qualitative approach would provide a richer insight into patients' perceptions of the process than that offered by the fixed response options of quantitative measures. Accordingly, there are no quantitative findings regarding psychological status to compare directly with those of Passik *et al.* (2004) or Chochinov *et al.* (2005). In the researcher's clinical opinion however, participants' emotional distress ranged from minimal to moderate upon entering the study. Consistent with Chochinov *et al.*'s (2005) findings, all patients reported gains from the intervention, irrespective of their perceived level of psychological distress.

4.4 Qualitative Findings

4.4.1 Overview of Patients' Perceptions of Dignity Therapy

The results of this study suggest that patients perceived dignity therapy to be a predominantly positive experience, similar to the findings of previous studies (e.g. Chochinov *et al.*, 2005; Passik *et al.*, 2004). In many ways, the core categories and sub-categories emerging from the analysis of patients' narratives mirror the existing literature, but some findings (e.g. unhelpful aspects of the intervention and the provisional framework) are unique, as will be discussed.

Core Category: Rapport

The first core category presented in Results was ‘rapport’. This reflected several patients’ remarks regarding their perceptions of a positive relationship with the researcher. Moreover, based on patients’ narratives, this affirmative relationship between the patient and the researcher appeared to facilitate the therapeutic encounter. The importance of rapport whilst working with palliative care patients has been addressed extensively in the literature, with much emphasis placed on the positive impact it can have on patients’ sense of self-worth and inclination to self-disclose (e.g. Chochinov, 2007; Kearney & Mount, 2000; Viederman, 2000).

Crow *et al.* (2002) conducted a systematic review of 139 articles discussing determinants of satisfaction with healthcare in general. They found much evidence across different clinical settings (e.g. GP practices and hospital inpatient and outpatient services) world-wide that the most important factor affecting satisfaction is the patient–practitioner relationship. Crow *et al.* (2002) cited qualities such as caring, concern, sensitivity and warmth as especially important. Several patients in the current study perceived similar qualities within the patient-researcher relationship.

Sub-Category: Listening

As outlined in section 3.5.1 of Results, several patients repeatedly mentioned their appreciation of the researcher’s undivided attention during the intervention, which they sometimes contrasted with their perception of limited listening by others. The importance of listening on the part of palliative care clinicians has been highlighted

frequently in the literature (e.g. Cassem, 2000; Jenko *et al.*, 2007; Noble & Jones, 2005). On the basis of patients' narratives, it would appear that the researcher demonstrated this key communication skill in her interactions with them.

Sub-Category: Compassion

Several patients also referred to perceiving the researcher as compassionate, which appeared to enhance their experience of dignity therapy. The importance of health professionals displaying compassion in their encounters has been cited by many palliative care writers (e.g. Higginson, 2007; Romanoff & Thomson, 2006; Rousseau, 2003). Therefore, patients' narratives suggested that the researcher was acting in such a manner, which is consistent with the principles of dignity-conserving care (Chochinov, 2007).

Perceptions of the researcher as acting in a collaborative, non-judgemental and respectful manner were also raised by some patients. However, there were not enough data to substantiate these features of the rapport as additional sub-categories.

Although these findings appear to relate neatly to some of the prerequisites identified for a successful patient-practitioner relationship in palliative care and in other healthcare settings, the researcher acknowledges that given the small number of narratives leading to the identification of 'rapport', this category requires verification via further dignity therapy research. Moreover, it is unclear from the results what features of the rapport were attributable to therapist-specific factors and which may be credited to rapport-enhancing features of dignity therapy itself. According to

Okiishi *et al.* (2003), cited in Freeman and Power (2007), the evidence suggests that the patient-practitioner relationship, regardless of the therapeutic approach used, can benefit patients. This point aside however, Chochinov *et al.* (2005) described the tenor of dignity therapy as ‘empathic, non-judgemental, encouraging and respectful’ (Table 1, p.5521). Perhaps both therapist-specific factors and the tone of dignity therapy were contributory factors in patients’ positive perceptions of the rapport. Furthermore, Kendall *et al.* (2007) reported palliative care patients’ appreciation of being listened to whilst participating in qualitative research. Therefore, it may be that simply being involved in this research contributed to patients feeling heard.

Core Category: Therapy

Evidence from the narratives suggests that the intervention was perceived by patients as ‘therapy’. Trueman and Parker (2004) reported challenges to the notion of life review as therapy. Similarly, the researcher had reservations before this study regarding whether or not dignity therapy warranted its title. However, she has since reconsidered this based on her observations during the process and the analysis of patients’ feedback.

Sub-Category: Looking Back

Patients described having found it helpful to look back over their lives whilst undertaking dignity therapy. This was in keeping with Fürst and Doyle’s (2006) assertion that looking back can be positive for patients. Narratives suggested benefits for patients similar to those of other life review processes mentioned in the palliative care literature. For example, Trueman and Parker (2004) wrote of life

review helping patients to emphasise positive facets of their past, which coincides with patients in this study highlighting the importance of revisiting happy memories during the intervention and feeling fortunate as a result. In addition, one patient spoke of a sense of calm on account of looking back which, in the context of their narrative, appeared to suggest increasing acceptance in the face of death. This is a benefit which Pickrel (1989) associated with general life review processes and McClement *et al.* (2007) attributed to dignity therapy. However, given that only half of the patients in the research presented here explicitly commented on the 'looking back' component of the intervention, further evidence is needed to elaborate this theme.

Sub-Category: Sharing Memories

As mentioned previously, several patients reported having appreciated the opportunity given by dignity therapy to share their often unspoken memories, both positive and negative. This appeared to be perceived by patients as more constructive than simply reflecting on their past, without sharing their story. This is consistent with Birren and Deutchman's (1991) claim (cited in Haight, 2003) that life review is best undertaken with another.

Benefits reported by patients mirrored many cited in the life review literature. For example, one patient spoke of ascertaining coherence in their life story, which coincided with Rodin and Gillies (2000) reports of life review providing an opportunity to (re)discover meaning in one's history. Another patient spoke of analysing their past interpersonal experiences whilst sharing their memories, which

they had found helpful. This appeared to support Trueman and Parker's (2004) claim that life review can help patients to increase their understanding of past relationships. An added bonus of participation for one patient was that the intervention jogged their memory about past events and the timing of them. This benefit echoes previous reports that life review can enhance one's memory (Birren & Deutchman, 1991). Also, two patients reported feeling that their story was valued by the researcher, in keeping with Chochinov's (2007) conditions for dignity-conserving care. Similarly, Romanoff and Thompson (2006) stressed the importance of giving patients with advanced illness a chance to share their story with a genuinely interested listener. Patients' feedback suggests that they perceived dignity therapy as providing such an opportunity.

The Regional Research Ethics Committee had been concerned originally that the DPQP questions were perhaps framed too positively, allowing little room for patients to discuss regrets. However, similar to Chochinov *et al.*'s (2005) study, patients shared memories associated with regret during this research, although these were by no means the focus of their accounts.

Sub-Category: Getting Things off Their Chest

Several patients' described having found it helpful during dignity therapy to articulate feelings and thoughts that have typically, but not always, remained unexpressed. As mentioned in section 3.5.1 of Results, this process appeared distinct from sharing memories and instead reflected the disclosure of *current* concerns (e.g. their diagnosis, funeral plans, unresolved family issues or future hopes for loved

ones). Fürst and Doyle (2006), writing about spiritual distress as death approaches, mentioned patients' desire for the resolution of outstanding issues. Similarly, Woodruff (1999) highlighted as important to dying patients the need to heal family relationships and conclude family affairs. The sub-category presented here incorporated such unfinished business.

Three patients mentioned that their disclosure of outstanding concerns was well-timed in light of their limited prognosis. Feelings of calm, pride and relief were attributed by patients to getting things off their chest. These references to enhanced emotional well-being support Chochinov *et al.*'s (2005) reports of the psychological and spiritual benefits of dignity therapy, as well as Haight's (2003) assertion that addressing unfinished business during life review processes can induce inner peace.

Of note, two patients mentioned their perceptions of being in a society, where emotional expression and open discussions of cancer, respectively are constrained. These comments fit with the researcher's experiences of Scottish culture, and possibly with much documented societal taboos regarding death and dying (e.g. Kendall *et al.*, 2007; Lee & Kristjanson, 2003). However, more research is needed to substantiate these remarks. Similarly, given the small numbers whose feedback brought about the theme of 'getting things off their chest', further evidence is warranted to validate it as a component of dignity therapy.

Sub-Category: Putting Their Story on Paper

As reported in section 3.5.1 of Results, several patients mentioned benefits from (a) 'making a book' and (b) 'editing the words' during the intervention.

a) Making a Book

In the case of 'making a book', some patients spoke of benefits for both themselves and family, as patients had done in Chochinov *et al.*'s (2005) study.

Impact on Patients of Making a Book

The researcher observed that whilst some patients had prepared their answers (e.g. having recorded dates and events on paper) before the sessions, others appeared to have made little or no preparation. Thus, embarking upon making a book appeared to be a highly significant event for some, whilst for others, it seemed less momentous, as reflected in the narratives.

One patient reported feeling optimistic that there was still much to live for on account of making their journal. For two others, making their journals inspired pride owing to its personal significance and its potential to help others, respectively. These comments support Chochinov *et al.*'s (2005) claim that this intervention can strengthen one's sense of hopefulness and purpose in life, as well as facilitating pride.

Of note, one patient, who spoke of feeling fortunate to have had the chance to document important messages for their family, stated that the timing of this process

was particularly good given their children's increased maturity and ability to understand the significance of the journal's contents. Had this patient made a journal at another time, its perceived benefits may have been less. Therefore, this feedback highlighted that undertaking this process needs to be timely for patients.

Potential Benefits for Family of Making a Book

Similar to Chochinov *et al.*'s (2005) participants, three patients cited potential benefits of the journal for their families. For one patient, the journal could provide a source of comfort for their family. This was a benefit reported by 77 per cent of bereaved respondents in McClement *et al.*'s (2007) study. This patient also perceived the journal as a means by which unacquainted others (e.g. their children's future partners) could get to know them after they were gone, which was also a benefit cited in McClement *et al.*'s (2007) study. Another patient felt that the journal would inspire others, whilst an additional patient spoke of the journal facilitating the recall of their child, who had forgotten the details of stories they had previously heard. These benefits appear to be consistent with Chochinov *et al.*'s (2005) finding that patients raised issues concerning generativity (i.e. their continuing influence after their death).

Although no patient cited potentially unhelpful consequences for family, it is acknowledged that a bias may have existed with regard to those who participated. Those who considered there to be potentially negative effects for themselves or their families may not have participated.

Resembling McClement *et al.*'s (2007) findings, the funeral eulogies of two patients in this study were prepared by their families based on their journal content. This suggests that patients' journals were highly esteemed by their families. However, without direct feedback from family members, it is impossible to report with confidence the true impact of dignity therapy on them. Future research should take McClement *et al.*'s (2007) lead and ascertain family members' perspectives directly.

b) Editing the Words

Several patients commented regarding the usefulness of co-editing their words with the researcher. Although the researcher and the Regional Ethics Committee had anticipated some resistance to this when patients had a point they wanted to make, such reluctance occurred in only one instance and even then agreement was reached quickly and amicably. Interestingly, this patient also expressed their appreciation of the researcher's help and advice during the editing process.

For some individuals, the editing process provided a second chance to rectify omissions (e.g. important events or persons) and inappropriate additions (e.g. disclosing private experiences of loved ones), or to reword passages (e.g. insensitive remarks regarding family members). Hence, these actions mirrored this process in the studies of Passik *et al.* (2004) and Chochinov *et al.* (2005). The editing process also allowed the researcher to clarify spellings of names mentioned by patients or words which were indistinct within audio-recordings.

Although most patients reported finding the editing process helpful, for one patient, the emotion induced by hearing their words read to them was perceived as somewhat unhelpful. As this patient's immobility necessitated the researcher wiping away their tears on each occasion, it may be that periods of emotionality were especially amplified for them. Previous studies of dignity therapy have not reported patients' perceptions of the editing procedure. However, Chochinov *et al.* (2005) observed that the editing process could often be emotional for patients.

Of note, negative case analysis showed that Patients 1 and 6 did not cite benefits related to 'getting things off their chest' and 'putting their story on paper'. For Patient 1, this is perhaps because they did not have issues they wished to discuss and they chose not to make a journal. Similarly, the researcher observed that Patient 6 did not discuss difficult memories or worries. This patient was also different from others given their previous experience of having their words documented and edited throughout their career. That said, although both patients' feedback differed to some extent from others, both expressed their appreciation of having participated in dignity therapy, reported personal benefits from doing so and recommended its use for others. Therefore, they also provided data to support the provisional framework.

Perceptions of Dignity Therapy as a Whole

a) Positive Aspects of Dignity Therapy

As mentioned in section 3.5.1 of Results, patients made additional comments regarding their perceptions of the whole process. Two patients mentioned finding

dignity therapy interesting. Another patient reported enhanced coping following the intervention, which appears to lend further support to Chochinov *et al.*'s (2005) claim of the intervention's capacity to improve emotional well-being. All patients' narratives suggested that they felt pleased that they had participated.

As well as mentioning emotions associated with the entire intervention, one patient cited a helpful, practical consequence – that is, simply informing their family about their participation resulted in useful family discussions.

b) Negative Aspects of Dignity Therapy

Although six of the eight patients reported perceiving nothing unhelpful about dignity therapy, two patients cited fatigue as a negative consequence of the intervention. One patient also suggested that the process should be shortened. To the researcher's knowledge, neither Passik *et al.* (2004) nor Chochinov *et al.* (2005) sought patients' feedback regarding unhelpful aspects of dignity therapy. Although McClement *et al.* (2007) reported some negative feedback about the intervention, this was from family members only. Therefore, the findings of the current research are unique.

Prior to granting approval, members of the Regional Research Ethics Committee expressed their concern that some DPQP questions were 'very Canadian' and 'wacky', respectively and may not appeal to patients in Scotland. However, when providing feedback regarding their experiences, no patient mentioned having an issue with the questions. Although three patients remarked during the intervention that the

question, '*When did you feel most alive?*' was difficult, all but one managed to provide an answer.

Whilst several of the benefits for patients in this research correspond to findings of previous dignity therapy studies (e.g. enhanced emotional well-being and making a book), many also fit with benefits reported from other life review processes (e.g. the opportunity to share memories and to get things off their chest). Consequently, it is unclear if dignity therapy is unique, as claimed by Chochinov *et al.* (2005). Moreover, it was suggested by Chochinov *et al.* that dignity therapy was distinct as a palliative care intervention given its ability to benefit both patients and family members. However, the researcher would argue that any life review process that involves making a book, such as the existing life review intervention available at the hospice studied, has the potential to impact both patients and book recipients.

That said, in the researcher's limited experience of life review, the clarity with which dignity therapy is described by Chochinov *et al.*, as well as its brevity, may distinguish it from other life review processes. Future research comparing dignity therapy with other protocols designed for life review with terminally ill patients (e.g. Jenko *et al.*, 2007) may further elucidate this issue.

4.4.2 Recommending Dignity Therapy

Seven participants stated that they would recommend dignity therapy to fellow patients, whilst the remaining patient remarked that others need to decide for themselves. However, some suggested that this process might not appeal to or be

helpful to everybody. Specifically, two patients highlighted that some individuals may not wish to disclose certain personal issues. These points echo Jenko *et al.*'s (2007) observations of patients' reactions to life review. Similarly, Garland (1994) cautioned that, 'life review is not a panacea' (p.29) and should not be undertaken with patients without careful consideration regarding its potential benefits for them.

4.4.3 Feedback Regarding Journal Format

All four patients who provided feedback regarding the journal format endorsed the researcher's design and none suggested improvements. However, it is acknowledged that they may have been unaware of alternative formats. Given that neither Passik *et al.* (2004) nor Chochinov *et al.* (2005) detailed the journal layout they used in their studies, it may be that the researcher's design, as described in section 2.7 of the Method and presented in Appendix 13, could be adopted during future applications of dignity therapy. However, further research is warranted to support the utilisation of this design, given the small number of patients providing feedback on it.

4.4.4 Home Interviews

Three patients who gave feedback regarding their home interviews were supportive of this context, the reasons for which included enhanced privacy, feeling relaxed, minimal distractions and the opportunity to share one's world outside the hospice with the researcher. Although based on small numbers, these findings support suggestions by both Passik *et al.* (2004) and Chochinov *et al.* (2005) that dignity therapy can be used successfully with patients in their own homes.

4.4.5 Family Members' Reactions

Although the researcher had expected family members to act as strict gatekeepers, in accordance with Hanks *et al.*'s (2006b) observations, this did not seem to happen in her experience. Based on patients' feedback and direct comments from children of two respective patients, family members' reactions were predominantly supportive of their loved ones participation in the research. Despite this however, the researcher acknowledges that the findings may be misrepresentative. There are pitfalls in relying on participants' proxy feedback regarding their family members' opinions. It is also possible that individuals whose families were not keen on the study did not participate, as in the case of one patient who initially consented, but later withdrew on the advice of their spouse. Future studies may benefit from including interviews with family members.

4.5 The Researcher's Reflections on Dignity Therapy

Based on the researcher's experience of delivering dignity therapy during this study and patients' perception of the process, this intervention seems to be feasible for patients with advanced illness in Scotland. The researcher agrees with Chochinov *et al.* (2005) that dignity therapy could be delivered by a range of health professionals with experience in psychosocial oncology, provided that they have access to the support of a psychologist or psychiatrist and supervision. Good therapeutic communication skills would also be essential. However, as mentioned previously, it remains unclear whether or not this intervention is unique. Moreover, it is important to highlight that transcription of the dignity therapy sessions can take many hours (e.g. 8-10 hours per one-hour interview). As noted by Passik *et al.* (2004), editing

the transcripts to compile the journal can also be a lengthy process. Therefore, hospice professionals would need to set aside a considerable amount of time to deliver this intervention.

4.6 Methodological Considerations

The researcher acknowledges that the study included methodological limitations as well as strengths and has endeavoured to interpret the findings with these in mind.

4.6.1 Limitations

Methodological limitations of this study relate to dignity therapy training, being a novice qualitative researcher, the researcher as the evaluator, responder bias, respondent validation, recruitment, selection bias, the sample, theoretical sampling, theoretical saturation and long-term follow-up.

Dignity Therapy Training

The researcher was unable to travel to Canada for supervised training in dignity therapy prior to the study. She was also unable to fund the trainer's journey to Scotland. Although she followed the published literature regarding this therapy as closely as possible, attended a dignity therapy lecture by Professor Chochinov in Scotland and had him inspect relevant sections of her anonymised write-up via correspondence, her delivery of the intervention may have been less rigorous given the absence of training. That said should such training, which is not easily accessible, be necessary prior to applying this intervention, its appeal to services may be limited.

Being a Novice Qualitative Researcher

The researcher acknowledges limitations of being a novice qualitative researcher. For example, she did not always recognise the importance of or document even the smallest comments made by patients walking back to the ward following a dignity therapy session. In hindsight, this is unfortunate, as many of these comments would have been invaluable to the analysis and unfortunately did not arise again in the research interviews.

The Researcher as the Evaluator

The researcher conducted both the intervention and research interviews. It is acknowledged that the lack of anonymity afforded by this approach may have impacted patients' honesty when giving feedback and potentially resulted in social desirability responding (Sitzia & Wood, 1998). However, recognising this risk, the researcher addressed the fact that patients might feel awkward giving negative feedback and strongly encouraged them to speak openly, emphasising the invaluable insight this would provide regarding the perceived impact of the intervention.

Responder Bias

Crow *et al.* (2002) alluded to other ways in which respondents' feedback might be influenced. These included cognitive consistency pressure (i.e. expressing satisfaction given one's wish to carry on using a service) and acquiescent responding (i.e. the tendency always to agree or reply positively). They also mentioned that cognitive dissonance theories forecast that individuals who have selected to use a service will not confess disappointment, as that would imply a contradiction in their

behaviour. Interestingly, Crow *et al.* (2002) additionally reported that older people usually express greater satisfaction than younger people, possibly due to (a) generational effects, in that older individuals are more tolerant or prompt more warmth from clinicians or (b) cohort effects, whereby earlier experiences of substandard services have reduced their expectations.

According to Crow *et al.* (2002), responder biases linked to the researcher's characteristics (e.g. accent, age, ethnicity or gender) may also emerge during interviews. As mentioned in section 3.5.1 of Results, the age-difference between the researcher and participants was raised by one patient. Also, the researcher's nationality was mentioned by three patients. Although perhaps unavoidable, these issues may have influenced the data obtained in this study.

Respondent Validation

As mentioned in section 2.10 of the Method, it was not ethically possible to involve these research participants in respondent validation, as most patients had deteriorated significantly or died by the time preliminary results were available. With hindsight however, perhaps aspects of the anonymised data, such as the findings regarding rapport, could have been usefully discussed with other specialist palliative care patients. It is unfortunate that respondent validation was not undertaken, as it would have strengthened the quality of this research.

Recruitment

The lengthy ethics process (approximately eleven months) for this study reduced the time available for recruitment to seven months. Moreover, the researcher had only one allocated research day per week in which to meet (potential) participants. Consequently, recruitment was a somewhat challenging process. Difficulties recruiting mirrored reports in the literature (e.g. Llewelyn *et al.*, 1999; Proot *et al.*, 2004). Twelve of the thirty-one patients identified were later deemed inappropriate and only eight of the nineteen patients approached completed the research process.

Despite written and verbal explanations regarding the research, some patients seemed to believe that the researcher would show their journal to other patients. It is possible that other potential participants declined to take part based on a similar misunderstanding.

Selection Bias

Kendall *et al.* (2007) reported researchers' difficulties with health professionals introducing a selection bias during recruitment in palliative care studies owing to over-protectiveness of patients. This was a possibility when the clinical team identified participants for this study. They may have put forward patients whom they considered keen to talk, whilst excluding others whom they deemed to be more private. If this occurred, it would limit the generalisability of the results.

The Sample

The sample in this research was small and from one hospice only. Like Chochinov *et al.*'s (2005) study, participants were predominantly old with advanced malignancies. This reflects the fact that 95% of the referrals to the hospice studied comprise malignant diagnoses, in keeping with referral figures for hospices elsewhere in the UK (Hospice Medical Director, personal communication, 8th January 2008). This restricted sample limits the generalisability of the findings to other age-groups and conditions. Accordingly, future research is warranted to determine the usefulness of dignity therapy with other samples.

Furthermore, only one male participated in this study. Of the nine males approached, two consented and one later withdrew. Accordingly, only 11.1% of males approached completed the study. In contrast, 70% of females approached did so, making up 87.5% of participants. Perhaps these figures reflect suggestions by Moynihan *et al.* (1998) and Charmaz (2006) that men may find therapy or intensive interviews uncomfortable, owing to the self-disclosure involved. In this study, one male who was approached voiced his suspicion of psychology, whilst another spoke of the focus of the study being 'too personal'. However, in Passik *et al.*'s (2004) study, 75% of participants were male, whilst in Chochinov *et al.*'s (2005) research, males comprised 56% of the sample. It is not known if males were purposefully recruited in these studies. It may be that the increased uptake by males was somehow associated with the cultural contexts examined.

Theoretical Sampling

As mentioned in section 2.1 of the Method, grounded theory incorporates theoretical sampling, whereby research participants are often chosen deliberately to gather more data in order to test early concepts and develop one's theory. Participants in this research were identified by the hospice clinical team and approached by the recruiter. Consequently, the researcher could not intentionally select participants to fill identified informational gaps. Moreover, given slow recruitment and time constraints, she could not be discerning regarding identified patients. Instead, concepts emerging in early interviews were incorporated into questions in subsequent interviews in an effort to gain the information sought. It is acknowledged that this restricted ability to undertake theoretical sampling may have weakened the provisional framework developed.

Theoretical Saturation

The breadth and quality of the information gathered varied significantly between patients, often due to fatigue and physical deterioration levels. The researcher's awareness of a patient's fatigue led her to avoid pursuing issues to the extent she would have liked, in order to maximise the chance of covering the most important areas. Although to be expected, it is felt that these physical issues had a significant part to play in the researcher's inability to reach theoretical saturation. While Dey (1999), Willig (2005) and Charmaz (2006) have challenged the realistic achievability of saturation, the researcher contends that given sufficient time and resources to recruit adequate numbers, theoretical saturation may perhaps have been achievable.

Long-Term Follow-Up

According to Freeman and Power (2007), benefits may become apparent some time after a therapeutic intervention, hence long-term follow-up is needed before evaluating the impact of a therapy. Given that patients in this study provided feedback immediately following the intervention, it may be that other benefits of dignity therapy were yet to become apparent. Although long-term follow-up is understandably problematic in palliative care settings, four of the participants in this study lived for at least three months post-intervention and could perhaps have been re-interviewed at a later point regarding the impact of the therapy.

4.6.2 Strengths

Despite its limitations, the researcher believes that this study had many strengths. These relate to communication, ethical rigour, qualitative methodology and supervision.

Communication

Although consistent with other researcher's experiences (e.g. Kendall *et al.*, 2007), the clinical team acted as strict gatekeepers to patients during the ethics process, once the study gained ethical approval, staff were very supportive. Throughout the study, good communication existed between both the recruiter and researcher, and the clinical team. The latter was kept informed at all stages of recruitment via verbal reports at the multidisciplinary meetings and Research Update Posters. They were also updated in person, as necessary, during subsequent stages of the study. Without such strong communication channels, this research could not have been completed.

Ethical Rigour

The researcher believes that this study was conducted with ethical rigour, as described in section 2.2 of the Method. The physical and emotional well-being of patients was constantly monitored and appropriate help was readily available should patients have needed it.

Qualitative Methodology

The qualitative approach used in this study allowed patients to describe freely their experiences and as hoped, shed some light upon previously untapped aspects of the intervention's impact. Had the researcher instead adopted a quantitative methodology, such as a questionnaire with closed response options, this would not have been possible. For example, Passik *et al.* (2004) used a five-point scale (where 1 represented 'strongly agree' and 5 represented 'strongly disagree') to measure patients' satisfaction with dignity therapy. However, given that patients chose '3' for many items on the questionnaire, they found that the usefulness of these responses was limited.

Supervision

The researcher contends that the regular meetings with and support of both her academic and clinical supervisors greatly facilitated this challenging research process. Academic supervision, along with practice, assisted in the advancement of the researcher's qualitative interviewing skills, whilst clinical supervision was an especially useful space within which to explore issues arising on the ground (e.g. managing interactions when encountering patients after their research participation).

Having transcripts read and coded independently by both supervisors, who were a consultant clinical psychologist with considerable experience in palliative care and a chartered health psychologist with experience of qualitative research in health care settings, further enhanced the quality of the research.

4.7 Contributions of this Study

In the researcher's opinion, this study makes four contributions to the field of palliative care:

- 1) It is the first, formal feasibility study of dignity therapy in the UK;
- 2) It lends support to some of the findings of both Passik *et al.* (2004) and Chochinov *et al.* (2005), such as patients' satisfaction with dignity therapy, emotional benefits as a result of the intervention and the feasibility of home interviews;
- 3) It provides some new insights into patients' perceptions of dignity therapy, including unhelpful aspects of the intervention and the overall provisional framework; and
- 4) It presents a potential format in which journals can be compiled during future applications of this intervention.

Since its initiation, this study has gained considerable interest by professionals working in palliative care elsewhere in Scotland and the UK, and interest has been expressed in extending this study to incorporate other regions. Moreover, it has been suggested that in addition to writing her own publication, the researcher become

involved in co-authoring a publication combining the results of dignity therapy studies worldwide. It is hoped that such intentions can be realised in the future and that this project's findings may facilitate future research projects in this area.

4.8 Reflections as a First-Time Researcher in Palliative Care

Similar to other palliative care researchers' experiences (e.g. Kendall *et al.*, 2007; Lee & Kristjanson, 2003), the researcher found the lengthy ethics procedure daunting. It was felt that several concerns expressed regarding the DPQP (e.g. that some questions were 'wacky') perhaps reflected committee members' personal taboos regarding death and dying and their limited knowledge of palliative care. Fortunately, the support of her supervisors, the clinical team and other interested individuals during the study restored the researcher's confidence.

Attrition due to deterioration or death is frequently problematic in palliative care research (Kendall *et al.*, 2007) and was a concern for the researcher. However, drop-out for these reasons was not so problematic in this study. Although two consenting patients withdrew prior to commencing the intervention and one patient withdrew after the first session of dignity therapy, it seems that only one of these patients withdrew due to their worsening condition. The remaining patients withdrew for personal, unspecified reasons. Fortunately, all eight participants successfully completed the protocol and received their final documents in time to present them to loved ones.

In the researcher's opinion, her clinical psychology training, which has involved a placement in specialist palliative care, was a major asset during this research process, especially in terms of her awareness of ethical issues, rapport-building skills, sensitive delivery of questions and ability to monitor patients' emotionality and fatigue. It is also likely that the researcher's prior experience equipped her to cope with the intensity of the topic better than she might have done without such prior exposure. However, the researcher's training as a therapist also made it difficult for her to adjust to a different interviewing style for the purposes of the research.

Laidlaw (2007) reported that it can often be difficult to keep older people focussed during discussions in therapy. Consistent with this, the researcher sometimes found it hard to redirect patients when they raised issues (e.g. receiving their diagnosis or loved ones' reactions to their illness) which were unrelated to the research topic, but often important to them. Although aware of her need to do so, she sometimes felt insensitive redirecting the conversation to the research agenda. However, she became more skilful with time.

Despite having repeatedly explained her role to patients and having used The University of Edinburgh paper for all documentation, the researcher noted that some patients' complimentary remarks about herself and hospice staff suggested that they perceived her as part of the clinical team. Consequently, it was sometimes difficult to ascertain if feedback was about dignity therapy itself or more generally about hospice care (e.g. patients' appreciation of having time made for them). Thus, only

those comments that the researcher was confident related to the intervention were analysed.

Although acknowledging that the process was intended to help them, six patients mentioned wanting to help the researcher. It was often difficult to gauge if this had a positive (e.g. pride) or a negative (e.g. anxious) effect on them, or if some patients had participated for this reason only. Nevertheless, these comments supported observations of other researchers (e.g. Ferrell & Grant, 2001; Kendall *et al.*, 2007) that some palliative care patients want to participate in research. Moreover, several patients mentioned their hope that their involvement would help other patients, as has been observed in other palliative care studies (Hopkinson *et al.*, 2005).

Although the interviews were often moving for the researcher, she was surprised by the extent of humour involved. This echoed Rigazio-Digilio's (2003) assertion that those who are dying often have an unbelievable ability to bond with and amuse others. Whilst patients shared their memories, the researcher learned much about the history of various parts of Scotland and enjoyed patients' descriptions of special moments, such as meeting their partners at local dance-halls during the War. The humorous, historical and extremely personal aspects of the interviews made them feel very rewarding and somewhat life-changing for the researcher, who greatly appreciated these individuals sharing their precious time with her.

Overall, the researcher feels that she has gained enormously both professionally and personally from undertaking this research. Moreover, she observed first-hand the

sense of appreciation and pleasure experienced by some palliative care patients as a result of their research participation.

4.9 Conclusion

The findings of this study suggest that palliative care patients at a Scottish hospice perceived this intervention in a predominantly positive light. The analysis showed that the rapport, in terms of listening and compassion, was perceived as especially helpful by patients. The analysis also identified four beneficial components of the intervention: a) looking back b) sharing their memories c) getting things off their chest and d) putting their story on paper, each of which appeared to benefit patients in emotional or practical ways. In addition however, a minority of patients identified some unhelpful consequences of the intervention. Consistent with the findings of Passik *et al.* (2004) and Chochinov *et al.* (2005), some patients also envisaged benefits of the process for their family. Based on their experiences, the majority of patients reported that they would recommend this intervention to fellow patients. These results endorse previous claims that this intervention is feasible for patients with advanced illness and may even benefit patients without observable psychological distress. Nevertheless, given the small sample studied, further research is needed to corroborate these findings.

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APPENDICES

APPENDIX 1

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

Patient Code: _____

Inpatient: Y N Outpatient: Y N

Age: _____

Sex: _____

Nationality: _____

Marital Status: _____

Highest Level of Education: _____

Religious Affiliation: _____

Diagnosis: _____

Date Intervention Began: _____

Length of Time Since Diagnosis: _____ months _____ years

Date of Death: _____

APPENDIX 2



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG
Telephone 0131 650 1000
or direct dial 0131 651

***A Scottish Trial of a Brief Intervention Based on Dignity Therapy:
The Experiences of Palliative Care Patients.***

Dignity Psychotherapy Question Protocol

- (i) Tell me a little about your life history, particularly the parts that you either remember most or think are the most important?**
- (ii) When did you feel most alive?**
- (iii) Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?**
- (iv) What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)?**
- (v) Why were they so important to you, and what do you think you accomplished in those roles?**
- (vi) What are your most important accomplishments and what do you feel most proud of?**
- (vii) Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?**
- (viii) What are your hopes and dreams for your loved ones?**
- (ix) What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parent(s), others)?**
- (x) Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?**
- (xi) In creating this permanent record, are there other things that you would like included?**

*A Scottish Trial of a Brief Intervention Based on Dignity Therapy:
The Experiences of Palliative Care Patients.*

Patient Code: _____

Date DPQP started: _____ Date DPQP ended: _____

Patient wishes to leave the journal to:

Name:

Relationship to Patient:

Address:

Patient does not wish to leave the journal to anybody, but to keep it: Y N

Patient wishes journal to be destroyed upon completion: Y N

Dignity Psychotherapy Question Protocol

Completed

- (i) Tell me a little about your life history, particularly the parts that you either remember most or think are the most important? ☐
- (ii) When did you feel most alive? ☐
- (iii) Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember? ☐
- (iv) What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)? ☐
- (v) Why were they so important to you and what do you think you accomplished in these roles? ☐
- (vi) What are your most important accomplishments and what do you feel most proud of? ☐
- (vii) Are there particular things that you still feel need to be said to your loved ones or things that you would want to take the time to say once again? ☐
- (viii) What are your hopes and dreams for your loved ones? ☐
- (ix) What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parent(s), others)? ☐
- (x) Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future? ☐
- (xi) In creating this permanent record, are there other things that you would like included? ☐

APPENDIX 3

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

Intervention Satisfaction Survey (ISS)¹

Patient Code: _____

Date of Interview: _____

Completed

- i) Based on your overall experience of the interviews, which involved looking back over your life and making a journal, would you recommend this process to other patients in the hospice? ☐
- ii) What, if anything, did you find helpful about the process? ☐
- iii) What, if anything, did you find unhelpful about the process? ☐
- iv) Is there anything else you would like to add regarding your experience of this process? ☐

¹ This comprises the core interview questions which have been designed for the purposes of this study to answer the research questions. However, by adopting a grounded theory approach, interviews were guided by the developing theory and the researcher asked additional, more direct questions relating to the emerging categories.

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

Intervention Satisfaction Survey (ISS)¹

Patient Code: _____

Date of Interview: _____

Completed

- | | |
|--|--|
| i) Can you tell me about your experience of going through this process with me from the first interview last week until you got your journal back today? | <input type="checkbox"/> |
| ii) What would you say to other patients about your experience of the process that we went through together?
Is there anything else you would say to patients about your experience of the process? | <input type="checkbox"/>
<input type="checkbox"/> |
| iii) What was it like for you to have your words edited for the final journal? | <input type="checkbox"/> |
| iv) Today I came along and gave you your final journal. What was it like for you getting that final journal? | <input type="checkbox"/> |
| v) What did you make of the journal layout or presentation? | <input type="checkbox"/> |
| vi) Is there anything that you would recommend to improve the journal? | <input type="checkbox"/> |
| vii) What, if anything, did you find helpful about the process? | <input type="checkbox"/> |
| viii) What, if anything, did you find unhelpful about the process? | <input type="checkbox"/> |
| ix) What did you make of the timing of the intervention? | <input type="checkbox"/> |
| x) Was there anything that you would recommend in terms of improving the process that we went through together? | <input type="checkbox"/> |
| xi) Based on your overall experience of the interviews, which involved looking back over your life and making a journal, would you recommend this process to other patients in the hospice? | <input type="checkbox"/> |
| xii) Is there anything else you would like to add regarding your experience of this process? | <input type="checkbox"/> |
| xiii) Could I ask you to <i>summarise</i> what you've told me today in your own words, based on looking back over the process we went through? | <input type="checkbox"/> |

¹ This comprises the core interview questions which have been designed for the purposes of this study to answer the research questions. However, by adopting a grounded theory approach, interviews were guided by the developing theory and the researcher asked additional, more direct questions relating to the emerging categories.

APPENDIX 4



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG
Telephone 0131 650 1000
or direct dial 0131 651

Dear

Re: *'A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients'*

My name is Audrey Matthews and I am a Trainee Clinical Psychologist. I have recently completed a part-time post in specialist palliative care and I now work most of my time in the cardiac rehabilitation and chronic pain services at the Department of Clinical Psychology,

Hospice. I am writing to invite you to take part in a new research study that I am undertaking as part of my Doctoral training in Clinical Psychology. The study has received the full support of the Clinical Research and Audit Committee at Hospice. It has also been approved by the Research Ethics Committee.

I am enclosing an information sheet about the study. Please feel free to discuss it with a family member or a friend. Fiona Cathcart, Consultant Clinical Psychologist, Hospice, who approached you about the study, would be happy to answer any questions you might have. You are also welcome to contact Professor , who has undertaken much research in palliative care and is not involved in this study, on

I have enclosed a consent form for you to sign, if you decide to take part. You can fill this in and give it to Fiona when she visits you again. I will then be in touch with you as soon as possible to arrange the interviews.

Many thanks for taking the time to read this letter and the enclosed information. If you would like any more information about the study, please contact the people named earlier. I would also be happy to answer any questions you might have, if you let Fiona know that you would like to speak to me.

Kindest Regards,

Audrey Matthews
Trainee Clinical Psychologist

Enc: Patient Information Sheet, Consent Form & DPQP.



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG
Telephone 0131 650 1000
or direct dial 0131 651

***A Scottish Trial of a Brief Intervention Based on
Dignity Therapy: The Experiences of Palliative Care Patients.***

You are being invited to take part in a research study. Before you decide if you want to take part, it is important for you to understand why this research is being done and what it will involve. Please take time to read this information and to discuss it with others if you wish.

What is the purpose of this study?

For many years, palliative care patients have been invited by health professionals to think about what is most important to them. Some write about their thoughts and experiences. This can help them to celebrate their past and some give this to a relative or friend to keep. From this, Canadian researchers have developed a new therapy called Dignity Therapy which is for patients receiving specialist palliative care. This therapy invites patients to talk about their lives and the most important things that they have learned. The results of research in Canada and Australia show that patients and families found it helpful. There is now research in the USA and Denmark also. However, there has not yet been research in the United Kingdom. It has been decided to find out if patients at a Scottish hospice find it helpful and think it should be offered to more patients in future.

Why have I been chosen?

You have been chosen because you are receiving specialist palliative care at Hospice. It is hoped that 10-15 patients will take part in this research.

Do I have to take part?

You do not have to take part in this study. The decision is entirely up to you. If you decide to take part, you will be asked to sign the attached consent form. You will still be free to withdraw at any time and without giving a reason. A decision to withdraw or not to take part will not affect the care you receive now or in the future.

What will happen to me if I take part?

If you decide to take part, I will meet you for 2-3 interviews. I will ask you some questions, which I have enclosed, about the parts of your life which you choose as the most important to you and the things you would want remembered. Each meeting will last about 45 minutes, but if you are tired it can be shorter and we can continue at another time. I will record these interviews so that I can write them out and give them back to you as a short journal and we will go through the journal together to see if you want any changes. If you wish to, you can give the journal to a relative or friend. If I think that some of the information may distress somebody, I will help you to edit it before the final journal is given to them. If it seems that any information could be harmful to the reader, it cannot be included. Afterwards, we will



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE

The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 651

Title of Study: *A Scottish Trial of a Brief Intervention
Based on Dignity Therapy: The
Experiences of Palliative Care Patients.*

Name of Researcher: *Audrey Matthews*

- | | Please
Tick |
|---|--|
| 1. I confirm that I have read and understand the Patient Information Sheet for the above study. I have also had the opportunity to consider the information and to ask questions which have been answered to my satisfaction. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I can withdraw at any time, without giving any reason and without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 3. I understand that if the interviews raise difficult issues for me, I can speak to staff (including the Clinical Psychologist) at Hospice about this. | <input type="checkbox"/> |
| 4. I understand that if the Researcher thinks that some of the information in my journal may distress somebody, she will help me to edit it. Information cannot be included if it seems potentially harmful to the reader. | <input type="checkbox"/> |
| 5. I understand that my responses to the research interviews will be reported anonymously and that it will not be possible to identify me in any subsequent write-ups. | <input type="checkbox"/> |
| 6. I understand that the Researcher will inform my GP of my decision to participate in this study. | <input type="checkbox"/> |
| 7. I hereby give permission for the Researcher to have access to my medical notes for the purposes of this research only. | <input type="checkbox"/> |
| 8. I have not participated in research with a psychological focus in the past two months. | <input type="checkbox"/> |
| 9. I am not currently involved in research with a psychological focus. | <input type="checkbox"/> |
| 10. I agree to participate in the study. | <input type="checkbox"/> |
| 11. I would like a copy of the study results. | Yes <input type="checkbox"/> No <input type="checkbox"/> |

Name of Patient

Name of Researcher

Signature of Patient

Signature of Researcher

Patient's Address

Date

Patient's Telephone Number (Day Hospice Patients Only)

Date



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Teviot Place
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***A Scottish Trial of a Brief Intervention Based on Dignity Therapy:
The Experiences of Palliative Care Patients.***

Dignity Psychotherapy Question Protocol

- (i) Tell me a little about your life history, particularly the parts that you either remember most or think are the most important?**
- (ii) When did you feel most alive?**
- (iii) Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?**
- (iv) What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)?**
- (v) Why were they so important to you, and what do you think you accomplished in those roles?**
- (vi) What are your most important accomplishments and what do you feel most proud of?**
- (vii) Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?**
- (viii) What are your hopes and dreams for your loved ones?**
- (ix) What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parent(s), others)?**
- (x) Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?**
- (xi) In creating this permanent record, are there other things that you would like included?**

APPENDIX 5

Hospice

Tel:

Medical Office Fax:

27th July, 2006.

Ms. A. Matthews,
Trainee Clinical Psychologist,
Department of Clinical Psychology,

Dear Audrey,

**'A Scottish Trial of a Brief Intervention Based on Dignity Therapy:
The Experiences of Palliative Care Patients'**

As Fiona will have told you, at their meeting yesterday, the 26th of July 2006, the Clinical Research & Audit Committee approved your research proposal.

I would be grateful if you could let us have a copy of the reply from the Ethics Committee for our records.

Yours/sincerely,

DR.
MEDICAL DIRECTOR

Ms. F. Cathcart, Consultant Clinical Psychologist,

Hospice



/approval/Matthews/2e
22nd November 2006

Miss Audrey Matthews
Trainee Clinical Psychologist
NHS /University of Edinburgh
Department of Clinical Psychology

RESEARCH &
DEVELOPMENT
OFFICE
Room

Tel: -
Fax:
Email:
R&DOffice@

Dear Miss Matthews

MREC No: N/A
CRF No: N/A
LREC No: 06/S1101/52
R&D ID No: 2006/P/PSY/19
Title of Research A Scottish Trial of a Brief Intervention Based on Dignity
Therapy: The experiences of Palliative Care
Protocol No/Acronym: N/A

The above project has undergone an assessment of risk to NHS and review of resource and financial implications. I am satisfied that all the necessary arrangements have been set in place and that all Departments contributing to the project have been informed.

I note that this is a single centre study sponsored by University of Edinburgh.

On behalf of the Chief Executive and Medical Director, I am happy to grant management approval from NHS to allow the project to commence, subject to the approval of the appropriate Research Ethics Committee(s) having also been obtained. You should note that any substantial amendments must be notified to the relevant Research Ethics Committee and to R&D Management with approval being granted from both before the amendments are made.

Please note that under Section A, Q35, NHS provides indemnity for negligence for NHS and Honorary clinical staff for research associated with their clinical duties. It is not empowered to provide non-negligent indemnity cover for patients. NHS does not provide indemnity against negligence for healthy volunteer studies. This is the personal responsibility of both NHS and honorary employees and is usually arranged with a medical reference organisation or through the University of Edinburgh.

This letter of approval is your assurance that NHS is satisfied with your study. As Chief Investigator or local Principal Investigator, you should be fully committed to your

responsibilities within the Research Governance Framework for Health and Community Care, an extract of which is attached to this letter.

Yours sincerely

R&D Director

- | | | |
|-----|---------------------------------|---|
| enc | Research Governance Certificate | <input checked="" type="checkbox"/> (to be signed and returned) |
| | NRR authorisation | <input checked="" type="checkbox"/> (to be signed and returned) |
| | Tissue Policy (if applicable) | <input type="checkbox"/> |
| | MTA (if applicable) | <input type="checkbox"/> (to be signed and returned) |

cc *Administrators, Research Ethics Committee*

NHS - UNIVERSITY HOSPITALS DIVISION

Research & Development Office,

Project ID: 2006/P/PSY/19

Project Title: A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The experiences of Palliative Care Patients

REC Ref: 06/S1101/52

Principal Investigator: Miss Audrey L Matthews

RESEARCH GOVERNANCE FRAMEWORK (RGF) FOR HEALTH & COMMUNITY CARE

The framework is of direct relevance to all those who host, conduct, participate in, fund and manage health and community care research. The framework applies to all managers and staff, in all professional groups, irrespective of seniority.

Research Governance

- Sets standards
- Defines mechanisms to deliver standards
- Requires monitoring and assessment
- Improves research quality & safeguards the public

Responsibilities and Accountabilities of Principal Investigator (PI)

The PI must take responsibility for the conduct of the research and is accountable for this to their employer, and, through them, to the sponsor of the research and to the care organisation(s) within which the research takes place or through which participants, their organs, tissue or data are accessed. The PI must have adequate qualifications and experience to take on these responsibilities.

In brief, they must ensure that:

- The dignity, rights, safety and well being of participants are given priority at all times by the research team.
- Ethical and management approval is obtained **BEFORE** study commences.
- Care professionals involved with patients are informed of study and its protocols.
- Study complies with all legal and ethical requirements e.g. data protection, informed consent & with RGF.
- Each member of the research team is qualified to discharge their role in study and that students are adequately supervised.
- When a study involves participants under the care of a doctor, nurse or other worker for the condition in which the study relates, those care professionals are informed that their patients or users are being invited to participate and agree to retain overall responsibility for their care.
- If any information relevant to the care of a patient arises through research, the patient's care professional must be notified. Unless, the patient or the relevant research ethics committee request otherwise.
- Reporting all adverse events, including adverse drug reactions through the appropriate systems.
- Controlled trials are registered.
- Research follows an approved protocol - any proposed changes or amendments to protocol are notified to the appropriate research ethics committee, sponsor and research host.
- Findings open to critical review through accepted scientific and professional channels and disseminated promptly.
- Key role in detecting and preventing scientific misconduct, by adopting role of guarantor on published outputs.
- Arrangements in place for financial management of the study and any Intellectual Property arising from it.
- All data are stored appropriately at end of study and are available for audit.
- Procedures are in place to ensure quality data are collected, processed, analysed, stored and archived
- Progress reports are sent to sponsors promptly and are of an acceptable standard

For further information and access to the complete Research Governance document visit: -

<http://www.show.scot.nhs.uk/cso>

Miss Audrey L. Matthews
Trainee Clinical Psychologist
NHS /University of Edinburgh
Department of Clinical Psychology

Telephone
Fax

Research Ethics Committee 01

Telephone:
Facsimile:
Email:

04 January 2007

Dear Miss Matthews

Full title of study: A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients
REC reference number: 06/S1101/52

Thank you for your letter of 30th November 2006, responding to the Committee's request for further information on the above research and submitting the revised documentation.

The further information was considered at the meeting of the Sub-Committee held on 20 December 2006.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	1	09 October 2006
Investigator CV	1	09 October 2006
Protocol	2	30 July 2006
Covering Letter	1	20 November 2006
Covering Letter	1	09 October 2006
Compensation Arrangements	1	28 July 2006
Questionnaire: Researcher's Copy of DPQP	1	30 June 2006
Questionnaire: Patient's Copy of DPQP	1	30 June 2006
Questionnaire: ISS	1	30 June 2006

Questionnaire: Dignity Psychotherapy Question Protocol	1	20 November 2006
Letter of invitation to participant	Letter 1 - 1	30 June 2006
GP/Consultant Information Sheets	1	09 October 2006
Participant Information Sheet: Patient Information Sheet	2	20 November 2006
Participant Consent Form: Patient Consent Form	2	20 November 2006
Response to Request for Further Information	1	30 November 2006
Message for Researcher (Inpatients)	1	30 June 2006
Suitable Inpatients List (South Team)	1	30 June 2006
Suitable Inpatient List (North Team)	1	30 June 2006
Message for Research (Day Hospice Patients)	1	30 June 2006
Demographics Sheet	1	30 June 2006
Suitable Outpatients List	1	30 June 2006
Letter from Hospice	1	27 July 2006
Supervisor CV	1	09 October 2006
Letter 4 - Interview Appointments	1	30 June 2006
Letter 2 - GP Letter re Patient consent	1	30 June 2006
Letter 3 - Patient's Participation Inappropriate	1	30 June 2006

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S1101/52

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

pp

Chair

*Enclosures: Standard approval conditions SL-AC1
Site approval form (SF1)*

Copy to: NHS Research and Development Group

Local Research Ethics Committee 01

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number: 06/S1101/52 Issue number: 1 Date of issue: 04 January 2007

Chief Investigator: Miss Audrey L. Matthews

Full title of study: A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients

This study was given a favourable ethical opinion by Local Research Ethics Committee 01 on 20 December 2006. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	Post	Research site	Site assessor	Date of favourable opinion for this site	Notes ⁽¹⁾
Audrey Matthews	Trainee Clinical Psychologist	NHS		20/12/06	

Approved by the Chair on behalf of the REC:

.....
(delete as applicable) (Signature of Co-ordinator)

{Name}

(1) The notes column may be used by the main REC to record the early closure or withdrawal of a site (where notified by the Chief Investigator or sponsor), the suspension of termination of the favourable opinion for an individual site, or any other relevant development. The date should be recorded.

APPENDIX 6

***A Scottish Trial of a Brief Intervention Based on Dignity Therapy:
The Experiences of Palliative Care Patients.***

Researcher

Audrey Matthews, Trainee Clinical Psychologist

Research Recruiter & Clinical Supervisor

Fiona Cathcart, Consultant Clinical Psychologist

Aim

This study aims to explore the experiences of palliative care patients in Scotland partaking in the first formal U.K. trial of a brief intervention based on Dignity Therapy (Chochinov *et al.*, 2005) and to ascertain whether or not patients' feedback suggests that this intervention should be routinely offered to palliative care patients. The Scottish Partnership for Palliative Care (2005), amongst others, pointed out that there is a crucial need for more research with patients at the end of life in order to develop an evidence-base for best practice with this patient population. This study may go some way towards contributing to this research gap. It will also hopefully help patients to celebrate their life, whilst addressing the spiritual matters arising from their illness.

Background

Chochinov *et al.* (2005) noted that there have been few non-pharmacologic interventions specifically designed to lessen patients' existential suffering towards the end of life, with most interventions aiming to simply make patients less aware of their distress. Accordingly, the authors presented a novel intervention, Dignity Therapy, designed to engender a sense of meaning and purpose, thereby reducing suffering nearing death. This intervention has previously been researched in Canada and Australia, showing positive outcomes for palliative care patients and family. An international randomized control trial of Dignity Therapy has also been funded in Canada, the U.S. and Western Australia. Dignity Therapy is additionally being trialled in Copenhagen at present. However, to our knowledge, this research will be the first formal trial of its kind in the U.K.

This study forms part of Audrey's Doctoral training in Clinical Psychology at the University of Edinburgh. It is being supervised by Fiona Cathcart, Consultant Clinical Psychologist,

Hospice and Dr. Paul Morris, Lecturer in Health Psychology, University of Edinburgh. The study has been approved by the Clinical Research and Audit Committee at Hospice, as well as Research Ethics Committee and Research and Development Committee.

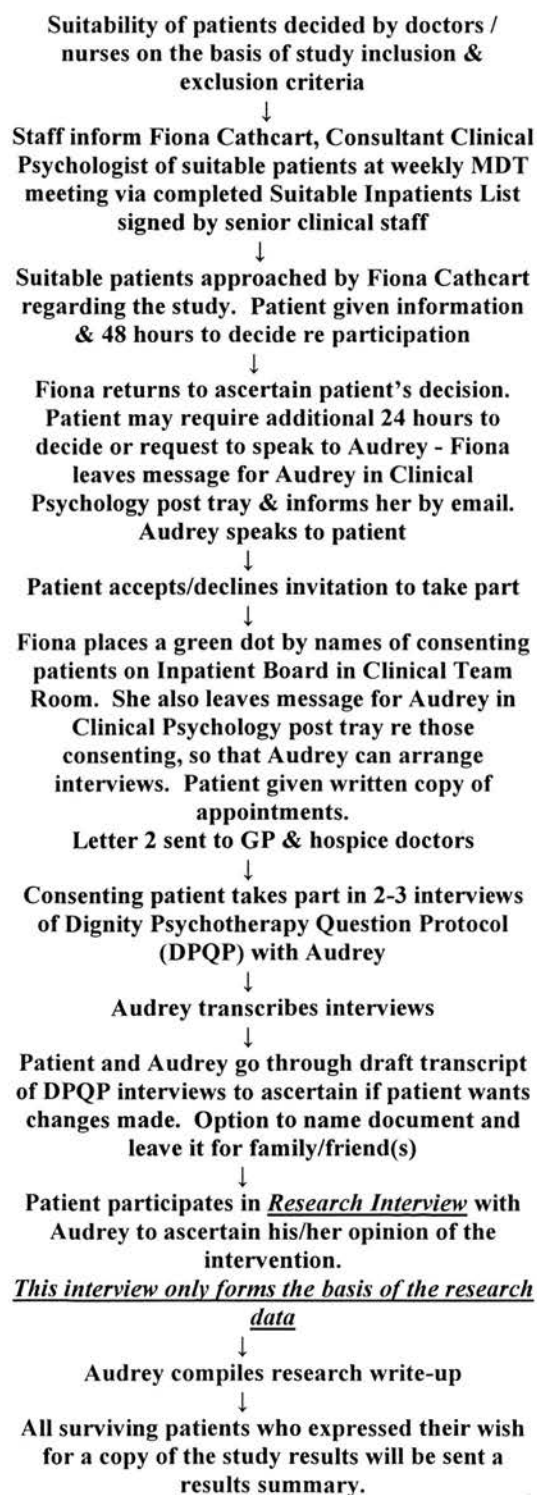
Intervention

Participants will be asked to partake in 2–3 sessions of Chochinov *et al.*'s (2005) Dignity Psychotherapy Question Protocol (DPQP) with Audrey. All sessions will be audiotaped and responses will be transcribed by Audrey at the earliest opportunity. When the DPQP is complete, Audrey and the patient will meet. The draft journal will be reviewed and the patient can request changes and a title before giving it to (a) family member(s) or friend(s).

Qualitative Research

Following the intervention, participants will take part in the Research Interview with Audrey. This interview aims to ascertain patients' views on the (un)helpfulness of the questions asked in the previous sessions using the DPQP. This interview will be audiotaped and transcribed by Audrey. These responses only (i.e. not the responses to the DPQP) will be analyzed using a qualitative approach based predominantly on Grounded Theory and

<i>Flow-Chart of Research Process</i>

Inpatients**Outpatients**

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

NORTH TEAM					
	Name	Room	Bed	Patient Decision	
				Yes	No
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					
	Signature: _____ Designation: _____ Date: _____			Signature: _____ Designation: _____ Date: _____	

Please see study inclusion and exclusion criteria overleaf

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

SOUTH TEAM					
	Name	Room	Bed	Patient Decision	
				Yes	No
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					
	Signature: _____ Designation: _____ Date: _____			Signature: _____ Designation: _____ Date: _____	

Please see study inclusion and exclusion criteria overleaf

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

DAY HOSPICE				
	Patient	Day Hospice Day(s)	Patient Decision	
			Yes	No
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				
	Signature: _____ Designation: _____ Date: _____		Signature: _____ Designation: _____ Date: _____	

Please see study inclusion and exclusion criteria overleaf

APPENDIX 8

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

Inpatients

Date _____

Dear Audrey,

_____ has been given the information regarding your study and would like to ask you some questions about it before deciding whether or not to take part. Could you please call to see _____ in Room ____ when you are next here?

Kind Regards,

Name: _____

Signature: _____

Job Title: _____

A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.

Inpatients

Date _____

Dear Audrey,

_____ has been given the information regarding your study and would like to ask you some questions about it before deciding whether or not to take part. Could you please call to see _____ in Room ____ when you are next here?

Kind Regards,

Name: _____

Signature: _____

Job Title: _____

'A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.'

Day Hospice Patients

Date _____

Dear Audrey,
 _____ has been given the information regarding your study and would like to ask you some questions about it before deciding whether or not to take part.
 _____ telephone number is _____. The best times to telephone are: _____

You can leave a telephone message: Yes ☐ No ☐

Kind Regards,

Name: _____

Signature: _____

Job Title: _____

'A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients.'

Day Hospice Patients

Date _____

Dear Audrey,
 _____ has been given the information regarding your study and would like to ask you some questions about it before deciding whether or not to take part.
 _____ telephone number is _____. The best times to telephone are: _____

You can leave a telephone message: Yes ☐ No ☐

Kind Regards,

Name: _____

Signature: _____

Job Title: _____

APPENDIX 9



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE

The University of Edinburgh

Medical School

Teviot Place

Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 651

Patient's Address

Date

Dear Patient,

Re: '*A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients*'.'

Many thanks for expressing your interest in taking part in my research at Hospice. The Clinical Team at the hospice have given considerable thought to your decision and unfortunately feel that the level of participation required for this study is likely to be too tiring for you just now. For this reason, I will not be contacting you to arrange interviews. However, I am most grateful for your interest in my study.

With every good wish,

Audrey Matthews
Trainee Clinical Psychologist

Cc Hospice doctors
Patient's GP

APPENDIX 10



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG
Telephone 0131 650 1000
or direct dial 0131 651

Dear

Re: 'A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients'

The following are the times that we have arranged to meet for the above research:

The appointments will take place at _____.

If you have any problems making it to these appointments, please do not hesitate to contact me on () and I can arrange alternative times with you.

I look forward to seeing you.

Kindest Regards,

Audrey Matthews
Trainee Clinical Psychologist

APPENDIX 11

*A Scottish Trial of a Brief Intervention Based on
Dignity Therapy:
The Experiences of Palliative Care Patients.*

RECRUITMENT UPDATE

7th May 2007

A big THANK YOU to everybody for identifying suitable patients for my research over the past few weeks.

I have now completed my intervention and Research Interview with three patients (one inpatient and two Day Hospice patients).

Unfortunately, those patients recently identified as suitable for my study, have been unable to take part for various reasons. In light of this, I am still looking for your help to identify suitable inpatients and outpatients. I would be really grateful if you could continue to complete the Suitable Patients Lists, which should be signed by a senior member of clinical staff and given to Fiona Cathcart, Recruiter for the study, at the weekly MDT meeting.

I will let you know as soon as I have recruited enough participants for the next series of interviews. If you have any questions in the meantime, please don't hesitate to contact me on /

Many Thanks,

Audrey Matthews
Trainee Clinical Psychologist

APPENDIX 12



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE

The University of Edinburgh

Medical School

Teviot Place

Edinburgh EH8 9AG

Telephone 0131 650 1000

or direct dial 0131 651

Date

General Practitioner
Address

Dear Dr. A,

RE: Mr. B, Address, DOB.

The above patient has been identified as being suitable for a qualitative study ('*A Scottish Trial of a Brief Intervention Based on Dignity Therapy: The Experiences of Palliative Care Patients*'), which forms part of my Doctoral training in Clinical Psychology. (S)he has been given information about the study (enclosed) and has consented to participation. The study aims to assess terminally-ill patients' perceptions of an intervention based on Dignity Therapy, which has been introduced by Chochinov *et al.* (2005) in Canada and Australia. Dignity Therapy aims to engender a sense of meaning and purpose in patients, thereby reducing suffering nearing death. Interventions based on this therapy have not yet been formally trialled in the U.K., hence this will be the first study of its kind.

The study has received the full support of the Clinical Research and Audit Committee at Hospice. It has also been approved by the Research Ethics Committee. Funding for the study has been provided by the Department of Clinical Psychology, University of Edinburgh.

Confidentiality will be maintained throughout the study for all records and reports. Nobody participating in this research will be identifiable in any subsequent write-ups or publications.

If you require any further information, please do not hesitate to contact me on ()

Yours sincerely,

Audrey Matthews
Trainee Clinical Psychologist

Cc Patient's Hospice Doctors

Enc Patient Information Sheet

APPENDIX 13

Looking Back

By

Betty Murphy

- (i) **Betty, can you tell me a little bit about your life history, particularly the parts that you either remember most or you think are the most important?**

Well I have fond memories of my childhood. I was born in the West of Scotland. I came from a big family. I was the youngest of 9. I had five brothers and three sisters! We had very little money, but our house was filled with laughter. There was always something going on. With so many wains, the house was pure mayhem, as you can imagine! My gran played a big part in our upbringing too hen. She was always popping in to help oot my mother and father, cooking the evening meal, doing the washing and all that kind of thing. My sisters, especially Rita, also looked after me a lot of the time too. When I think back, they were awfy good to me.

Do any particular memories from your childhood stand out in your mind Betty?

Aye, so many! I remember my oldest brother Danny going away to the priesthood. My parents were so proud of him, but sad to see him go. He'd been a great help to my father, who was a cobbler. I can still see my mother's face as she waved goodbye to him. You'd think he was off to Australia and him only going up the Highlands!

My other brothers worked in the shipyards on the Clyde and my sisters helped oot at a local woollens factory. They got me a job in the back-office there when I left school. I must've been about thirteen at the time. The house used to be like a train station in the mornings, everyone fighting to get washed! We worked hard for very small wages and we gave it all to oor parents. They needed every penny. My parents looked after my grandfather when my gran died, so there were lots of mouths to feed.

So how long did you work at the factory?

About two years I think, and then the War was finished. My aunt was a seamstress and she took me under her wing. She was a hard task-master, but it was all good training. My mother used to say that it didnae do me any harm!

You mentioned the War. Are there memories from that time that you think are important to mention?

Aye, we had all the rations of course. Not easy times, but we were all in it together, and we made oor fun. We had many a sing-song in the back room and the neighbours would come in with a tin whistle or a fiddle. Rita had a great singing voice and we would sit around the fire while she sang.

How was life after the War finished?

Oh it got better after the War. Everybody started to relax again and people were putting the War behind them. It was like a black cloud was lifted. Rita got married soon after the War ended and we all had great fun preparing for the big day. Dressing up was something we didnae get to do very often, so we were all very excited! My aunt was called in to dress us for the occasion. I remember wearing a knee-length lilac dress and I felt like a princess. Although we were happy for Rita, we were all sad to see her move

out, because she was the life-and-soul of the house. When she told us she was moving to Edinburgh, there were tears. In those days, Edinburgh felt like a long way away!

What were the important things that happened in your life after that then Betty?

Well the important things in my life after that were family things really, my other sisters getting married and the arrival of nieces and nephews. Of course, as I got older, I started going to the local dances too with my cousins and my pals. My parents were quite strict, so in the early days, I had to beg them for permission to go, but with time, it got easier.

You're smiling a lot. I take it that they were enjoyable times!

Oh yes! I was always at the dancehall whenever I could. I *loved* dancing. My mother used to say that I was born dancing! That was when I started to meet some nice laddies and it wasn't long before I laid eyes on the man I ended up marrying!

Do you want to tell me a wee bit about the man who stole your heart?

Oh I remember the moment well. I'd left the hoose after an argument with my brother, Gerard. I cannae mind what it was about, but I do mind that I was in a bad mood! I remember noticing this laddie smiling over at me from across the dancehall and I couldnae help, but stop scowlin'! He was there with a big group and the first chance he got, he was over asking me to dance. The rest is history really!

I met him in 1948. I was nearly sixteen then, or was it seventeen? We got married just after my twentieth birthday. What a day! Even though we couldnae afford a very fancy affair, we were so happy. My aunt made me the most beautiful dress. It was quite plain and simple, but I felt so pretty that day and I remember the sun shining for us.

So what was your husband's name Betty?

Tommy. I just lost him three years ago. He had an awfy bad heart and eventually it was heart failure that got him. I never thought I'd manage a day without him, but my family have been so good to me. I still miss him every day though.

Did you want to say a wee bit about married life?

Oh aye! They were great years. In the beginning, we had a lot of hardship. Everybody did, but things got easier over the years. Then I had my daughter, Patricia in 1954 and my twin boys, Ewan and Malcolm in 1957. So you can imagine the noise in the house with three babies under the age of four! My mother was a life-saver and my sisters were always at hand when they werenae busy with their own bairns. We were always a family to help one another oot whenever we could. Tommy's family were great too. I was awfy close to his sister, Sally and she would come round every Saturday and lend a hand. You don't get so much of that kinda thing now. Families arenae so big and dinnae get so involved in each others' lives.

Were there any other memories you wanted to mention?

No, I think they were the main ones really. If you let me, I could probably talk for hours, so best to move onto the next question I think!

(ii) When did you feel most alive Betty?

I think after the War finished, when my parents let me go dancing. I felt so care-free and the world felt like a safe place again. I had so many friends who lived in the same tenement or the ones close by. We had no concept of the difficulties young folk have to face nowadays. Life was simpler back then!

You smile a lot when you talk about the dancing!

Yes! I have so many lovely memories from those days. In fact, we were only looking at some old photos the other day that I'd forgotten all about. Tommy was so handsome when I met him! I felt very lucky to have caught his eye!

(iii) Are there specific things that you would want your family to know about you and are there particularly things that you would want them to remember?

I think they ken everything about me already hen! We're not ones for secrets.

Is there anything particular that you would like them to remember about you Betty?

Well, I would like people to remember me for the happy-go-lucky person that I try to be and all the silly wee things. I hope when I'm gone that they remember that I was always here for them no matter what matter. They should already know that I love them and I always will.

(iv) What are the most important roles you've played in life – family roles, vocational roles, community service roles?

Well, being a mother I suppose and rearing my beautiful daughter and my boys. There were times when they were a handful, but we managed. Tommy was a great father, always willing to help. My mother always said that I landed on my feet when I met him! Not like my sister Mary whose man took a drink and knocked her about. (NB - Needs to be edited).

Are there other important roles that you've played in your life?

As a wife I suppose, though it's one you could easily forget! I'm not sure what Tommy would say if he was here now, but he used to always say that I made him happy. We had oor wee rows like anyone, but we didnae let it linger. The pair of us were pretty easy-going. Tommy used to joke that I was like his personal secretary. If it wasnae for me organising him, he wouldnae ken what he was supposed to be doing on a day. My mother used to say the same. I was always organising everyone, not in a bossy way, ken? I was just always the one making arrangements and planning family events.

Any other important roles you feel that you've played in life?

I looked after Rita before she died. She had a stroke and she always said that if anything ever happened to her after Jack died, she didnae want to end up in a hospital somewhere being cared for by strangers. So I looked after her at mine for about seven months. I had to get some help from her daughter and my neighbour, Cathy. She's a nurse, but between us we managed not too bad.

And I know you told me that you did a lot of charity work Betty, so that's a community role.

Yes, I suppose it is. My neighbour was always involved in some charity thing or another. One year long after the kids had left home, she asked me to help oot with the Christmas cake-sale for the parish hall and it was a great success. After that, I got involved in all sorts of things - sponsored walks, charity raffles, this and that. I even used to collect money for the hospice. Little did I think that I'd be needing it hen!

Are there any other important roles that you've played?

That's been all the main things I can think of really.

(v) Why were those roles so important to you and what do you think you accomplished in those roles?

Well, I just feel that I've helped a lot of people. Looking back reminds me how much I've been involved with helping other people and that just makes you feel good, doesn't it? I was never one to be idle - I always had some sort of project on the go! Tommy used to laugh. He'd say, 'Would you ever sit still woman!' but I just couldnae.

(vi) Betty, what are your most important accomplishments and what do you feel most proud of?

I feel proud of my children, very proud and Tommy used to say that too. They've all done well for themselves, but they've put in the work to get there. They've never caused me a minute's trouble and I know that it could've been different. You hear stories nowadays of children getting into all sorts of bother and it tears families apart. I don't think my children ever caused me a sleepless night, apart from when they were getting their teeth! So I'm proud of them and I've told them that.

Are there any other accomplishments that you feel proud of in your life?

Well, I think that Rita would've been glad that we kept her at home. It wasnae easy and Cathy used to say that we should try and get some extra help, but we managed. Rita did so much for me growing up. I feel that I've at least returned the favour a wee bit.

- (vii) **Are there particular things that you still feel need to be said to your loved ones or things that you would want to take the time to say once again?**

The only things I can say to them are things that I've already said. They are so special to me and I appreciate everything that they've done for me, especially since Tommy died and since getting my cancer. I'd be lost without them.

- (viii) **Betty, what are your hopes and dreams for your loved ones?**

That they're happy and healthy. My children have been very fortunate, though it hasnae always come easy. I want them and their children to stay as healthy as they are now and to keep enjoying life. I hope that they dinnae let work take over their lives and that they keep sharing some happy times with their own wains. I hope that my two granddaughters finish their studies and have the opportunity to travel. They both want to see the world and with travel being so easy nowadays, why wouldn't they? Sarah is studying to be a nurse and Susan is training to be a teacher, so they should be able to get jobs abroad quite easily.

So your hopes and dreams are very much about happiness, health and enjoyment.

That's it in a nutshell hen!

Anybody else that you've got hopes and dreams for?

Well I think the only one I havenae mentioned is my grandson. I don't think I've got to really worry about him. He's doing so well for himself. I think he's going to be a very famous journalist some day. He's already met President Clinton and Sean Connery! He tends to take it all in his stride.

- (ix) **What have you learned about life that you would want to pass along to others, or what advice or words of guidance would you pass along to your children or other people who are close to you Betty?**

Well, I think that love is the most important thing in life. There's a lot of love in wer family and sometimes we take that for granted, but not everybody is as lucky as we are. Mary wasnae as lucky with her man. (NB - Needs to be edited).

Dinnae go to bed on an argument. We all have wer wee tiffs, but nothing is worth falling oot over. Dinnae be too proud to say you're sorry.

- (x) **Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?**

The only thing that I can tell them is to live for the moment. Life is very precious, but nowadays, it has become so fast that people miss out on many of the simple, wee things. Enjoy your wains when they're wee before they grow up. It'll happen in a flash and there's no going back! Celebrate when there's cause to celebrate and dinnae be shy about standing tall when you've done something worth shouting about.

- (xi) In creating this permanent record, are there other things that you would like included?

I'd like to say to all my family that I've done my best for them and I'm very proud of them. I mightnae say it as often as I should, but I couldnae ask for better children.

*Interviews recorded on the 14th and 21st May 2007 at the hospice by
Audrey Matthews, Researcher for her study, 'A Scottish Trial of a Brief Intervention
Based on Dignity Therapy: The Experiences of Palliative Care Patients.'*

APPENDIX 14

Initial Coding

MEMOS	INTERVIEW TRANSCRIPT	CODING
	R*: (Patient 7), can you tell me about your experience of going through this process, which involved looking back over your life and making a journal?	
<u>New code</u> Unhelpful aspect of dignity therapy/editing process (see comments later in interview)	P7*: It was quite <u>emotional</u> ...	Emotional
	R: Mm-hmm.	
	P7: ...and eh, <u>I didn't think I could speak to the point</u> ...	Expecting difficulty expressing oneself
	R: Ok.	
<u>New code</u> Helpful consequence of making a book/journal	P7: ...but I <i>did</i> make it and I think it's quite a <u>good thing to leave behind for people to know, who've not had a chance to know me</u> , so that might give me an idea, then an idea...	Expressing oneself Means by which unacquainted others can get to know me
	R: Mm-hmm.	
<u>New code</u> Helpful consequence of making a book/journal	P7: ...as to <u>what kind of a person I was</u> .	Means by which unacquainted others can get to know me
	R: Ok. So you said to me there (Patient 7), 'It was quite emotional'...	
	P7: Yes!	

* R: Researcher

* P7: Patient 7

Initial Coding

MEMOS	INTERVIEW TRANSCRIPT	CODING
	R: ...in terms of your experience going through the process.	
Editing Process	P7: No, just <u>somebody else reading it out to me...</u>	Hearing own words
	R: Ok.	
Editing Process	P7: ...cos when you say on a regular basis, <u>you don't seem to realise...</u>	Not realising impact of words
	R: Mm-hmm.	
Editing Process	P7: ... <u>till you hear it from somebody else...</u>	Hearing own words
	R: Ok.	
Editing Process	P7: ... <u>the impact it has</u> , so it was quite <u>emotional</u> .	Realising impact Emotional
	R: Ok. Was there anything else you wanted to say about your experience of going through the process with me, apart from the fact that it felt emotional?	
In keeping with comments of P2, P3 & P8	P7: Well, as I say, it might give somebody a chance to say something which they may not have said otherwise...	Opportunity to open up/ Getting things off their chest
	R: Ok.	

Initial Coding

MEMOS	INTERVIEW TRANSCRIPT	CODING
<p>P2 & P4 have also repeatedly remarked about how open they are. I wonder if certain types of people are participating in this study?</p> <p>Have the clinical team introduced a selection bias by identifying as suitable those who seem most open?</p>	<p>P7: ...but in my case, <u>I've said again and again</u> to the family.</p>	<p>Being Open</p>
	<p>R: Mm-hmm.</p>	
<p>Positive emotions re making a book</p>	<p>P7: ...so it was just like em a, em, what you say? <u>Reiterating</u> the fact that I have made it telling them and then hearing them again and again just made me think, 'Yeah, <u>I am lucky</u> that I have told them what I should have...'</p>	<p>Reiterating messages</p> <p>Hearing own words</p> <p>Feeling lucky</p>
	<p>R: Ok.</p>	
	<p>P7: '...rather than some people not making it.'</p>	
	<p>R: Ok.</p>	
<p>In keeping with comments of P2, P3 & P8 – this seems to be especially important for P7</p>	<p>P7: So <u>it's a chance for people who can't speak a lot for themselves or let their emotions be known to others...</u></p>	<p>Opportunity to open up/ Getting things off their chest</p>
	<p>R: Mm-hmm.</p>	
	<p>P7: ...so that gives them <u>a window</u> to you know, say it.</p>	<p>Opportunity to open up/ Getting things off their chest</p>

APPENDIX 15



Section of Clinical and Health Psychology
SCHOOL OF HEALTH IN SOCIAL SCIENCE
The University of Edinburgh
Medical School
Teviot Place
Edinburgh EH8 9AG
Telephone 0131 650 1000
or direct dial 0131 651

***A Scottish Trial of a Brief Intervention Based on
Dignity Therapy: The Experiences of Palliative Care Patients.***

In August 2007, you took part in this research and requested a copy of the final results. A summary of these is presented below.

Who took part in this study?

Eight patients (six inpatients and two outpatients) receiving specialist palliative care at Hospice participated in this research. These comprised 1 male and 7 females, ranging in age from 50 to 87 years (mean 73.38, SD 11.78). Patients were Scottish, Indian and Irish.

For how long did patients participate in the study?

Completion of the Dignity Psychotherapy Question Protocol (DPQP) required between 1 and 3 sessions (mean 1.88; SD 0.83). These were followed by a Draft Review Meeting to edit the journal and a research interview to determine patients' perceptions of the process. Total patient contacts ranged from 3 to 5 (mean 3.63; SD 0.92) and total days over which contacts were spread ranged from 4 to 42 days (mean 22.75; SD 12.31).

For whom did patients make a journal?

Seven patients requested journals following the DPQP, with the numbers requested ranging from 1 to 8 copies (mean 3.25; SD 2.60). Journal recipients included patients and their relatives.

What did the analysis of patients' feedback find?

Patients perceived this intervention in a predominantly positive light. The relationship between the researcher and the patients, in terms of listening and compassion, was viewed as especially helpful by participants. The analysis also identified four components of the intervention: a) looking back b) sharing their memories c) getting things off their chest and d) putting their story on paper, each of which appeared to benefit patients in emotional or practical ways.

What did patients think was helpful about the intervention?

Patients valued the opportunity to look back over their lives, especially the happy times. Sharing their memories appeared to be particularly helpful, rather than reflecting on their

past on their own. It was also helpful to express feelings and thoughts that have typically, but not always, remained unarticulated. This process seemed to be different from simply sharing memories and instead relates to the disclosure of current concerns (e.g. diagnosis, funeral plans and unresolved family issues). Many patients also appreciated the opportunity to make a journal about their life and the important messages they wished to pass on. Based on patients' comments, all seemed glad that they had participated in the intervention.

What did patients think was unhelpful about the intervention?

Two patients identified unhelpful aspects of the process. Both cited fatigue as an issue, whilst one added that the intervention was too long and should be shortened. The remaining six patients stated that they considered nothing unhelpful about the process.

In what ways did patients think their journal might impact their families?

Some patients anticipated potential benefits for their family as a result of having made a journal. These included the journal providing comfort and inspiration, jogging their memories about stories they had previously heard, as well as a means by which unmet others could get to know patients after they were dead.

Would participants recommend this intervention to other patients?

Based on their experiences, seven patients said that they would recommend this intervention to fellow patients, whilst the remaining patient remarked that others need to decide for themselves. However, some suggested that this process might not appeal to or be helpful to everybody, as some individuals may not wish to disclose personal issues.

What contribution do these findings make?

These results endorse previous claims that this intervention is feasible for patients with advanced illness and may even help those with no observable psychological distress. However, given the small numbers studied, further research is needed to confirm these findings.

What will happen next?

I will submit my Doctoral thesis in February 2008. I will then present the findings to clinical staff at Hospice and to interested health professionals in other services. I also hope to publish the results in medical journals. All results will be reported anonymously. Therefore, no participant will be identifiable in any report.

I would like to thank you once again for taking the time to participate in my research.

With every good wish,

**Audrey Matthews
Researcher**